MASS. HS 33.2:P94

Project TIES

Training in Expanded Services

Caring for Severely Disabled Children in Family Settings

Trudy Latzko, Director
Project TIES

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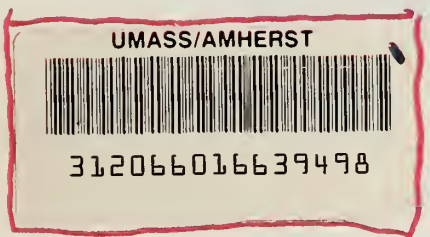

Massachusetts Department of Public Health
Division of Family Health Services
Community Services Unit

Supported in part by a grant from the Massachusetts Administering Agency for Developmental Disabilities (Grant #86-1-10).

HS 33.2:P94

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MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH
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Commonwealth of Massachusetts

Michael S. Dukakis, Governor

Phillip W. Johnson, Secretary of Human Services

Deborah Prothrow-Stith, Commissioner of Health

February, 1988

Acknowledgements

I am indebted to the following professionals who are the primary presenters at the 41 workshops being held throughout Massachusetts by Project TIES during Spring 1988:

Cynthia Taft Bayerl, R.D., M.S.	Administrator, Nutrition Program Department of Public Health, Boston.
Susan Berliner, M.Ed., L.C.S.W.	Social Worker, Boston Children's Services Association, Boston
Ilene R. Boroda B.S., R.P.T.	Physical Therapist, Northeast Regional Health Office, Tewksbury
Sherry Braun, M.P.H., R.D.	Pediatric Nutrition Specialist, Developmental Evaluation Clinic, Children's Hospital, Boston
Robert Brockman, B.S.	Co-Director Project Access World; Director, Rehabilitation Engineering, Mass. Hospital School, Canton
Meredith Brouillette, M.S., R.D.	Nutrition Consultant, Kennedy Donovan Center, New Bedford; Private Practice
Martha Butler M.S., R.N.	Psychiatric Mental Health Nurse Educator, Kennedy Memorial Hospital, Boston
Sherrill Butterfield, Ph.D.	Co-Director of Education, Children's Extended Care Center, Groton
Nancy A. Caldwell, M.S.	Speech/Language Pathologist Mass. Hospital School, Canton
Ruth Crowley, M.S., CCC-SLP	Speech-Language Pathologist, Kenndy Memorial Hosp. Brighton
Amy Ebersole, M.S.	Speech/Language Pathologist, Mass. Hospital School, Canton
Rosemary Gonneville, B.S., R.P.T.	Physical Therapist, Southeast Regional Health Office, Lakeville
Lynn L. Graff, M.A., CCC-SLP	Department Head, Speech and Language Pathology Services, Mass. Hospital School, Canton
Barbara Hodge, M.C.S.P., R.P.T.	Neurodevelopmental Physical Therapist Instructor, Private Practice, Needham

Martha Sue Hoffman, M.S.	Speech/Language Pathologist Tufts-New England Medical Center, Boston
Pat Joyce, O.T.R.	Occupational Therapist, Western Regional Health Office, Northampton
Deborah Kranefuss, P.T.	Director of Physical Therapy, Children's Extended Care Center, Groton
Betty Landrigan, R.P.T.	Physical Therapist, Northeast Regional Health Office, Tewksbury
Tricia Leahy, P.T.	Physical Therapist, Mass. Hospital School, Canton
Ellen Levy, M.A., C.A.G.S.	Coordinator, Recruitment Plus Project, Department of Public Health, Boston
Sharon Lee Marcus, M.S., CCC	Speech/Language Pathologist, Mass. Hospital School, Canton
Barbara McLetchie, Ph.D.	Co-Director of Education Children's Extended Care Center, Groton
Judith Mounty, Ph.D.	Director, The Language Program; Director, The Program for the Deaf and Hard of Hearing, Special Education Collaborative, Hingham
Jesse L. Munn, R.N., M.S., C.R.R.N.	Director of Nursing, Children's Extended Care Center, Groton
Sue Murray, B.S., R.P.T.	Supervising Physical Therapist, Southeast Regional Health Office, Lakeville
Alma Perry-Correia, R.P.T.	Pediatric Physical Therapy Supervisor, Mayflower House Nursing Home, Plymouth
Linda Piette, M.S., R.D.	Nutritionist, Professional Center for Handicapped Children, Andover; Private Practice
Amira Pellet, Ph.D., R.D.	Nutritionist, Baystate Medical Center, Springfield
Theresa E. Rowse O.T.R./L	Occupational Therapist, Children's Extended Care Center, Groton
I. Leslie Rubin, M.D.	Director of Medicine, Children' Extended Care Center, Groton
Julie Rutkowski, M.S., R.P.T.	Supervisor, Rehabilitation Services, Western Regional Health Office, Northampton

Ellyn Salkin-Cohen, M. Ed.	Behavior Specialist, Boston Children's Service Association, Boston
Maggie Sauer, M.S., CCC-SLP	Communication Specialist, Communication Enhancement Clinic, Children's Hospital, Boston
Amy H. Scheps, M.S.	Speech/Language Pathologist, Mass. Hospital School, Canton
Dick Schnell, Ph.D.	Director of Psychology, Developmental Evaluation Clinic, Children's Hospital, Boston
Margo Stitt, P.T.	Physical Therapist, Children's Extended Care Center, Groton
Roberta Thomas, M. Ed.	Early Intervention Education Specialist Massachusetts Office of Deaf and Hard of Hearing, Boston
Deborah Willard, R.N., B.S.	Nurse Coordinator, Children's Extendend Care Center, Groton

I would also like to thank the following administrators and their staffs of the sites where meeting space, equipment and the opportunity to observe children have been afforded:

Susan De Cristofaro	Director of Hospital Administrative Services, Mass. Hospital School, Canton
Burt Downes	Director of Clinical and Social Services, Berkshire Children's Community, Great Barrington
Joseph Hallett	Director of Pediatrics Kenndy Memorial Hospital, Boston
Vicki Takki	Education Director/ Coordinator, Mayflower House Nursing Home, Plymouth
Carol Lobron	Administrator, Children's Extended Care Center, Groton
Kevin O'Grady	Executive Director, North Shore Special Education Consortium, Peabody

Introduction

The goal of Project TIES is to help expand the system which delivers services to severely disabled children. By increasing the knowledge and confidence of those who care for these children we can also increase the likelihood that severely disabled children will remain in a family environment.

The objective of the training program is to support and encourage participants in becoming key providers of care for medically involved children with multiple handicaps by:

- obtaining a fund of knowledge and a better understanding of the disabling conditions of childhood
- learning specific care and management measures applicable to the children they care for
- learning what community resources are available to them

Project TIES training is not intended to replace client specific training which one should receive prior to caring for a child. Parents receive this help from hospital discharge staff and from other professionals such as their child's physician and therapists; home health care personnel receive this guidance from their supervisors. Since the roles and job responsibilities of health care providers vary among employing agencies, all care and management techniques presented in these workshops may not be applicable to the roles of all those participating in this training.

NORMAL DEVELOPMENT: ADAPTATIONS FOR THE DISABLED CHILD

Objectives

After completing this unit, participants will:

1. Identify the premises of the developmental approach.
2. Discuss how the normal characteristics and developmental tasks of each stage of development impact on the disabled child.
3. Formulate strategies to help the disabled child achieve optimal development.
4. List ways in which the physical environment can be adapted to help the disabled child play, learn and interact with others.

Developmental Tasks and the Disabled Child

All children are alike and all children are different. Each child has the same developmental tasks to accomplish. Each child has the same needs for a nurturing, stimulating environment; one that encourages physical, mental and emotional development. Each child has his or her own temperament, personality, strengths, weaknesses, and family and cultural background. Each child deserves the opportunity to develop to the fullest extent possible.

Premises of the developmental approach are:

- Life is a process of change.
- Human growth and development is orderly, sequential and predictable.
- All persons have the capacity for growth.
- The rate and direction of growth can be influenced by environmental and supportive factors.

Theories of growth and development have different focuses. Erik Erikson divides the human life cycle into eight stages and identifies psycho-social tasks for each. Jean Piaget examines cognitive development, Skinner and others use a behavioral approach and Kohlberg has given us a way to view the stages of moral development. All of these theories have value in helping us understand and care for children. Our discussion today will try to synthesize these theoretical approaches by looking at the characteristics and tasks of childhood and how we can help the disabled child attain the goals of each stage of development.

Stages of Development

INFANCY (Birth - 1 1/2 years)

Normal characteristics

- dependency
- demand of immediate gratification

Tasks

- develop sense of trust
- develop awareness of self as loved and worthy of attention
- develop object constancy--out of sight is not out of mind
- develop mobility and skillful use of fingers
- develop understanding of words

The Disabled Child

Parent/infant relationship is stressed by:

- parent's grief
- lack of normal feedback from child
- hospitalizations, therapy sessions
- altered early experiences on the child's part

Early detection and intervention is important

Attitudes of parents affect child's future relationships with others

Experiences with professionals will color future relationships

Emphasis on normalization may be difficult

Infant doesn't know he or she is disabled

TODDLER (1 - 3 years)

Normal characteristics

- increase in development of motor skills and drive
- toilet training accomplished
- important language gains--two-word sentences
- conflict between pleasing others and getting own way
- responds more readily to action than to words

Tasks

- develop sense of competency
- develop sense of autonomy versus sense of doubt
- delay of gratification--patience
- problem solving
- self control
- toilet training
- learn to cooperate, share

The Disabled Child

Retarded children may not reach this stage until 3 - 5 years of age or even older. The impairment of the child's motor, sensory or cognitive skills will impede exploration. Stimulation and intervention will be needed.

- Socialization is needed to avoid the negative feelings of being different
- Parents may have difficulty in "letting go" so child is denied sense of competence
- Balance between restriction and overprotection is important
- More patience is needed so that child develops self-esteem

PRESCHOOLER (3 - 6 years)

Normal characteristics

- egocentric--sees things only from his or her point of view
- eager to explore and learn
- wants to identify with parents
- interested in sexual characteristics
- attachment to opposite sex parent

Tasks

- develop sense of initiative versus sense of guilt
- establish sexual identity
- self mastery, competence

The Disabled Child

- development continues to lag; child begins to understand that he or she is "different"
- identity is affected by parent's emotional state (e.g., depressed parent) and by ambivalent parental view of child
- poor self regard may affect initiative and creativity
- training in responsible sexual behavior begins

SCHOOL AGE (6 - 12 years)

Normal characteristics

- expresses self energetically
- assumes responsibility at school and home
- develops relationships with other children, especially those of the same sex
- wants to be independent
- peer approval important; conforms

Tasks

- develop sense of industry versus sense of inferiority
- increase skills
- develop peer relationships
- accept and adjust to reality

The Disabled Child

- desires to be like others but has difficulty being accepted; child feels pain of being different
- lack of social experience leads to fewer friends
- decrease in effectiveness of play for the discharge of emotions
- school is a primary socializing agent, as a result of limited activities
- increase in intellectual abilities allows child to understand his or her problems
- because of past experience with professionals, parents may be reluctant to share information with school authorities
- failures become more obvious; dependence on parents increases, although there is a natural drive toward independence
- parent/teacher communication needed to help prevent child's social isolation; child will benefit from a social/activity group

ADOLESCENCE (12 - 19 years)

Normal characteristics

- moodiness
- body image is very important
- strives toward independence, making own decisions
- thinks about future
- sexual/social relationships become all-important
- able to think in abstract terms

Tasks

- develop sense of identity versus role confusion
- become independent
- increased emphasis on personal hygiene
- mobility
- increase skills to prepare for future work
- assume responsibility
- develop good communication skills
- develop self-discipline

The Disabled Child

Independence issues

- child's preference regarding personal appearance should be respected, especially if he or she is dependent on parent or attendant
- child should be allowed to participate in decisions regarding what they are able to do; emotional dependence can be more handicapping than physical dependence
- child needs privacy
- allow child to assume as much responsibility for own medical care as possible
- good communication with family, peers, attendants and community is vital to attainment of independence

Disciplinary measures need to:

1) give child choices in decision making
2) note specific behavior
3) tell how you feel
4) give reasons for feeling that way

(continued)

Sexual issues should be dealt with openly

- recognize child as a sexual being
- help learn age appropriate, responsible behavior
- teach child about contraception
- shouldn't be told that they can't manage parenthood
- adoption and sterilization are options
- Deal openly and honestly with masturbation

If teenager is depressed, get counseling for him or her

Adapting the Environment

If the child is assisted in participating in as many of the normal activities as a non-disabled child enjoys, his or her self image and self esteem is supported. Normalization allows the child to attain as much independence as posssible and increases opportunities to play, learn and interact with other children and the community. Part of this process involves adapting the physical environment. Some examples include:

BEDROOM

- material for stimulation over child's bed
- positioning bed so that child will be turning to the side of body which is not favored
- hammock useful

(continued)

- seating adapted

  a. corner chair

  b. bean bag

  c. adjustable heights for chair

  d. footstool

  e. plastic stacking chair with three sides

Toys

  a. horse on wheels

  b. adapt a pinball machine by using a foot pump to propel marbles

  c. looseleaf book to make turning pages easier

  d. pen holders keep pens steady in a block of wood

- work light for visually impaired and markings around doorways, cupboards and primary landmarks

- earphones which adjust to high volume for the hearing imoaired

- alarm clock attached to vibrator positioned under mattress

BATHROOM

- bathing chair

- shampooing screen or swim mask

- thermostat faucet

- soap bag filled with scraps; easier to grip than soap bar

- soap on mitt, wash mitt

- bath towel poncho slips over child's head

- lower mirror

- non-slip mats or paint on bathroom floor

CLOTHES

- key ring on zipper for easy operation
- raglan sleeves
- boatneck sweaters
- velcro instead of buttons
- use of a bandana instead of bib for older child who drools
- jumper-apron can hide braces
- bar on wall or door handle can aid child in dressing
- sitting in corner of room or side lying may be positions which aid in self-support
- special pocket for hearing aid
- special markings and consistent placement for visually impaired

KITCHEN/DINING ROOM

- extra table leaf mounted on table
- Tripp Step Chair
- special utensils
- rotating plate for child who can't use utensils
- straws; thick and colorful
- contrasting color mat on table for definition

PLAY

- investigate toy lending library
- hanger with stimulating materials attached to wall
- bells on shoes

(continued)

- magnetic games that can be adapted to be operated with chin or forehead
- feather sensitive controls for games, electric trains
- boating mug for setting glass in
- hand straps for maracas
- sponges instead of paint brushes
- jump rope with special handles
- balls with and without sound; color and contrast important
- stimulating materials within reach of visually impaired
- other adaptations for visually impaired include:
  - investigate hobbies; e.g., birdsongs on tape
  - handrope to encourage mobility
  - tandem bike
  - sheet music in Braille
  - wheelchair skis fasten under wheels

OUTDOORS

- recesses in sand and water tables to accommodate wheelchairs, prone boards
- special rubber swim trunks for children with diapers
- horseback riding programs
- cart which is pulled behind bicycle to allow child to remain positioned correctly

Workshop 1

BIBLIOGRAPHY

1. Bower, T.G.R. A Primer of Infant Development. San Francisco: W.H. Freeman and Co., 1977.

2. Bowlby, John. Child Care and The Growth of Love. Baltimore: Pelican Books, 1953.

3. Chess, Stella and Alexander Thomas. Temperament in Clinical Practice. New York: The Guilford Press, 1986.

4. Erikson, Erik H. Childhood and Society. New York: W.W. Norton & Co., 1950.

5. Klaus, M. and J. Kennell. Maternal-Infant Bonding. St. Louis: C.V. Mosby, 1976.

6. Kohlberg, L. The Development of Children's Orientation Toward a Moral Order: 1. Sequence in the Development of Moral Thought. Vita Humana, 1963, 6, 11 - 33.

7. Montague, Ashley. Touching. New York: Columbia University Press, 1972.

8. Moustakas, Clark. The Child's Discovery of Himself. New York: Ballantine Books, Inc., 1966.

9. Piaget, Jean. The Origins of Intelligence in Children. New York: W.W. Norton & Co., 1963.

10. The Nordic Committee on Disability. The More We Do Together; Adapting the Environment for Children with Disabilities. New York: World Rehabilitation Fund, Inc. 1985.

11. Waldstein, Arnold; David Gilderman; Denise Taylor-Herschel; Sonya Prestridge and Joan Anderson, (Eds). Issues in Neonatal Care. Washington: U.S. Dept. of Education, Contract # 300-80-0753, 1982.

Mostly I Can Do More Things Than I Can't.

ILLINOIS SPECIAL NEEDS ADOPTION PROJECT

ILLINOIS DEPARTMENT OF
CHILDREN AND FAMILY SERVICES

GORDON JOHNSON, DIRECTOR

SELECTED DISABLING CONDITIONS OF CHILDHOOD: WHAT A PARENT MIGHT NEED TO KNOW

Miriam Kalichman, M.D.

Prospective parents thinking about adopting children with special needs, or caseworkers working with these families, may have questions about some of the common disabilities of childhood. Sometimes the diagnostic label is frightening or poorly understood. A diagnostic label never suffices as a description of any particular child. However, knowing what is meant by the terminology and having a general sense of what a disease entails may help a family or caseworker ask appropriate questions about one particular child. In this section, I will attempt to describe some of the common chronic handicapping conditions of childhood in general terms.

The two most common physical disabilities of childhood are cerebral palsy and spina bifida. Overall, the most common developmental disability is mental retardation, which occurs in some 2 percent of all children. Many children whose primary difficulties are related to mental retardation also have physical disabilities, and many children whose primary problems are severe physical disabilities also have retardation to a greater or lesser extent, so these problems cannot be completely separated.

Mental Retardation

Mental retardation is a term used to describe people who have difficulty learning. This means that what they learn requires more careful and repetitive teaching, that they learn more slowly than the average person, and that they are less able to think up ideas and connections between ideas themselves, but rather need other people to show them the connections. Learning does not refer only to academic subjects such as reading or counting but also to social skills and self-care. In fact, the definition of mental retardation specifies that adaptive behavior is impaired, as well as academic learning. Mentally retarded children frequently do not learn to play with their toys in an imaginative way without being shown, frequently do not learn such self-care skills as feeding, dressing, or using the toilet as early or as easily as other children, and frequently do not learn to make social judgments, such as deciding who is friendly and who is not, learning to obey rules, or being polite, as quickly as other children do.

Mental retardation is divided into classes based on severity. Children who are educably mentally retarded, or mildly mentally retarded, benefit from special education. They frequently can learn basic school subjects, such as reading and simple arithmetic, although these skills may take many years to acquire. Often they can learn to develop friendships, play, and develop good work habits and—depending on how well they are raised and whether they have other medical or

physical problems—can frequently live with some supervision but not dependently as adults. Usually they are able to maintain friendships with other children who are not mentally handicapped.

Trainable, or moderately retarded, children typically are slow at learning to speak. As they grow up, their language tends to be concrete and related to what is immediately at hand and not reflect the past, the future, or emotions or abstract concepts. Trainable children also benefit substantially from special education, which is usually geared toward helping them learn social skills and self-care skills such as dressing, cleaning up, following directions, and performing household tasks. Most retarded children are mildly mentally retarded, and the vast majority of such children are mildly or moderately retarded.

Severely retarded children generally do not develop useful language. They may learn a few words. They generally take a much longer time to attach to parents and attach like young babies even when they are much older. They tend to enjoy simpler kinds of infant or toddler games as they grow. Special education is usually geared at helping them pay attention and learn to understand some words, and helping them learn to cooperate with self-care routines.

Profoundly retarded children are those who will likely never develop language and may not be able to differentiate between one caregiver and another. They cannot be toilet-trained or learn to feed or care for themselves. Special education for them usually consists of general stimulation efforts and attention to other problems. The more severely or profoundly retarded a child is, the more likely it is that he or she also has physical disabilities and medical problems.

Some people confuse mental retardation with learning disabilities. A person with a learning disability has specific problems with one or more of the pathways to learning but has the capacity to understand as much as an average person. A child with a learning disability might learn, not by listening, but by reading. He might not be able to match letters to sounds in his mind, so that he would be able to read silently but not to pronounce what

he sees or spell what he hears. He might not be able to figure out geometric shapes by looking at them, or he might have difficulty remembering the order of a series of steps. Some people with learning disabilities are very bright; most are average. Special education for children with learning disabilities consists of teaching them grade-level material with methods that use their "normal" learning styles, and teaching them how to work around their problems. Learning disabilities remain throughout life but may be less apparent or even seem like personality traits in adulthood.

Some people also confuse the term "developmental disability" with mental retardation. People who are mentally retarded do have a developmental disability, but not all people with a developmental disability are mentally retarded. A developmental disability is defined as a severe, chronic disability which is mental and/or physical and manifested before the age of 22, is likely to continue throughout life, and substantially limits functioning in three or more of the following activities: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. The condition requires individualized, interdisciplinary services of extended duration.

Down Syndrome

The cause of mental retardation can sometimes be easily found and sometimes does not seem to be associated with other problems. Although most cases do not have a cause identified, the most common identified cause is Down syndrome. Down syndrome occurs in one of 600 or 700 children. People with the condition have an extra chromosone 21 or a part of it in some or all of their cells, depending on how the genetic accident occurred. Because the defect is in all cells, the way all cells in the body hook together and work together is distorted to some extent. This explains some related disabilities that people with Down syndrome have. They tend to have the same type of facial features. Their eyes tend to slant, and there is flattening in the middle part of their faces. They are typically short and round with

small heads which are flat in back. They tend to have short, stubby hands with a single line across the palm, and short, stubby feet. Often they have loose, floppy muscle tone which can interfere with early physical development and feeding. Most, but not all, children with Down syndrome are diagnosed shortly after birth because of the characteristic face.

Medical problems are quite common in children with Down syndrome and should be looked for. Many of the children will have early difficulty eating and growing. Even in children without growing difficulties, short stature is the rule. A fourth to a third of such children have congenital heart disease. Usually this can be treated surgically, but not every procedure will be successful, nor can all heart defects be corrected. About 10 percent of newborns with Down syndrome will have abnormally formed intestines, requiring surgery. Perhaps a fourth of the children will develop thyroid problems, but these can usually be managed easily with medication. About 10 percent have problems with the alignment of their spines because of the looseness of their muscles and ligaments. This can cause serious problems with movement and bladder and bowel control, and occasionally sudden death. Most of the time the problem can be identified before complications arise. Because of common muscular problems, difficulties in handling mucus, and head shape, children with Down syndrome tend to have frequent colds and ear infections. Many will need ear surgery and careful evaluation of their breathing. Some other medical problems are common in the syndrome but cannot be predicted easily, including leukemia.

Most children with Down syndrome are in the trainably retarded range. Some, however, are profoundly retarded, and some are only mildly retarded. Extent of retardation usually cannot be predicted in infancy.

Sadly, it is now becoming clear that many people, more than half, with Down syndrome will ultimately develop Alzheimer's disease. This is a disease which generally occurs in older adults in the normal population, causes gradual loss of memory, judgment, and other mental skills, and cannot be corrected. It is ultimately fatal. All of aging is accelerated in adults with Down syndrome, so that many have old-age arthritis and inelastic skin; physiologically they seem older than their age. Alzheimer's tends to occur much earlier in people with Down syndrome than in others, and this likely accounts for the shortened lifetime in people with the syndrome. We can expect most of these people, with good medical care and no heart disease, to live into their 40s.

Adolescence is usually delayed in children with Down syndrome, and sexual interest is usually delayed and less compared to other teenagers. Men with Down syndrome are not able to father children; very few pregnancies have been reported in women.

Fetal Alcohol Syndrome

Fetal alcohol syndrome is another common cause of mental retardation. At this point, however, no one

is sure how many children are born each year with the syndrome. It seems to be associated primarily with children of heavy drinkers, but not all heavy drinkers have affected children. In general, children with the condition, if severely affected, are very small at birth and remain small, although they do grow. They generally have small, narrow heads, down-slanted eyes, and flat faces. Severe vision and hearing problems may occur, as well as heart disease. Retardation occurs in all ranges, from mild to severe. Although growth and development are both improved with good family care, as compared to care by a chronic alcoholic, neither growth nor mental development can be made normal by a normal environment.

Other Causes

There are many other causes for mental retardation. Some of these are other genetic defects, malformations of the brain, injury to the brain in the early newborn or prenatal period, and infections or injuries of the brain in infancy and childhood. Additionally, many people seem to be normally formed but slower to learn, and these tend to be in the mildly retarded range. It is important to try to find out why a particular child is retarded. If a diagnosis can be made, one can anticipate certain problems that are known to occur in a diagnostic class. Additionally, some causes of retardation can be helped with diet or drug therapy, and some causes will be important for the biological family. However, not knowing a cause for retardation does not mean that treatment, which is special education and good parenting, must wait.

Autism

Autism is a specific type of severe developmental disorder. It can arise from a number of biological problems and can also appear without any obvious cause. Autism begins in early childhood, between six and 30 months. The children do not develop normal language, although they may know a number of words which they use in unusual ways. They do not tolerate change easily and tend to do the same thing over and over and to become panicked in a new environment.

Perhaps the hallmark of autism is difficulty in relating well to others. The child may not seek out his mother for comfort or may not seem to know that the mother is different from any stranger on the street. Because of difficulty in using language and in being aware of and caring about other people, helping these children learn is extremely difficult. It is hard for them to concentrate and understand what is being asked. Most autistic children are boys. Some are mildly autistic with relatively good, although somewhat stereotyped, ability to respond to family members, and some use of langage. Others seem to be locked into a world of their own, constantly whirling and shutting out other people. Children with some relationship skills and early language can be taught to develop self-care and social skills. More severely impaired children often make very little progress. Children with autism frequently have seizures (although these usually do not

develop until the teenage years) and may have other medical illnesses or disabilities as well.

Cerebral Palsy

Cerebral palsy is one of the physical disabilities of childhood. The name encompasses as broad a range of problems as does the term retardation. In the condition, brain damage occurs in the neonatal or prenatal period and affects the person's ability to control muscle tone. to control posture against gravity, and to control voluntary movements. Some two children in every 1,000 have cerebral palsy. It cannot be diagnosed at birth. It can usually be diagnosed before one year of age and always by two. Although many children with cerebral palsy are known to have complications in the neonatal period, such as prematurity, bleeding within the brain, or difficulty in getting breathing started, not all children with cerebral palsy will have such a history.

One can describe what parts of the body are hardest to control with several other diagnostic modifiers. A person with quadriplegic cerebral palsy has very limited movement, not only in all four limbs, but also in the head, neck, trunk muscles, and facial muscles. A person with hemiplegic cerebral palsy has impaired control and use of muscles on either the left or right side of the body, with nearly normal function on the other side. A person with diplegic cerebral palsy has involvement throughout his body, but much worse in his legs than his arms. Cerebral palsy can be spastic, in which the limbs are usually held tight and rigid, or athetoid, in which there are waving, writhing movements that interfere with movements the person wants to make.

Early development in children with cerebral palsy is quite slow. Normal babies move in reflex patterns, but they quickly break out of these and develop the ability to move one muscle at a time and never really move the same way twice in a row. The hallmark of cerebral palsy is trouble with tone and postural reflexes. This means that the body tends to be held rigid

and in an attitude which depends on the position of the head. Because severely affected children are not able to move their extremities independently from their heads, they will not be able to get their hands to their mouths, will not be able to roll, and will not be able to lift their heads while lying on the stomach. If they do not get appropriate therapy, these patterns become fixed and will gradually cause joint deformities because the joints are not moving freely in different patterns. The baby may be sore and irritable because his muscles are tight all the time. Facial muscles of a severely affected child are also affected; the baby may be unable to eat adequately because his tongue may be so poorly coordinated that he spits food out, or he may bite down on the spoon involuntarily. It also may be difficult to seat the baby so that he is comfortable being held and fed. Rapid movement, sound, or bright light may also activiate the "startle" reflexes that gradually disappear in normal babies. Children with the condition also tend to have spasticity in the muscles of their eyes, which may cross and interfere with normal vision development. Their difficulty in feeding and tightness in the muscles controlling the mouth and middle ear can lead to ear infections and hearing loss. Children with cerebral palsy are frequently constipated and have difficulty with spitting up. This affects their growth and also makes them uncomfortable.

A mildly affected child may pass some early milestones such as picking his head up or rolling, but the way he does these may be unusual. A hemiplegic child is generally diagnosed when the difference between his sides becomes noticeable at the end of the first year of life.

Perhaps the most devastating problem with cerebral palsy is the inability to learn and communicate normally. A normal baby learns by watching his hands, being able to turn his head to follow sounds and things in his visual field, being able to make a variety of sounds that interest other people, and being able to move, to reach, and to explore things with his hands and mouth. A child who cannot lift his head will have a difficult time paying attention to what other people can see right in front of them. A child who cannot move will not be able to explore his room, get his own toys, or play peek-a-boo with his mother. A child who has serious problems with feeding may be too exhausted to do anything else after eating. A child whose sitting is delayed will not have his hands free to learn how to stack, bang, or pick up fine objects.

About half the children with cerebral palsy are also retarded, but there is no correlation between how severe the movement problem is and how bright the person is. About a third also have convulsions. The incidence of hearing and visual problems is also higher in children with cerebral palsy than in normal children.

Nearly all children with cerebral palsy will require early and intensive physical, occupational, and speech therapy to help them learn more normal patterns of movement, to show parents how to continue the therapy at home, and to develop equipment to help

keep them in positions in which they function best. The prognosis for walking cannot be given in an infant who has all four limbs involved. In general, one can best give the parents a prognosis after a child has been healthy and getting good solid therapy for a year or two. Therapy will never make such a child normal but may make him much more able to learn, move about, take care of himself, and communicate. Except in the most severe cases where feeding is nearly impossible, cerebral palsy does not shorten a person's life expectancy. It is not a genetic disorder, and people with the condition can be found in almost every profession, living independently and raising families.

Spina Bifida

Spina bifida is the most common life- and function-threatening malformation in human beings. In the United States, it occurs in one or two per 1,000 babies, varying widely in severity.

The condition is almost always diagnosed at the moment of birth, if not before, and is believed to occur in the first month of pregnancy. Nerves which form the spinal cord and bones surrounding the spinal cord do not form normally. A normal spinal cord takes messages from body surfaces about limb position, pain, and other sensations up to the brain and returns with messages from the brain regarding how to move the muscles. This system is disrupted in spina bifida. Depending on where in the spine the defect has occurred, movement, feeling, and growth are affected. Because bladder and bowel sensation and control are carried by nerves at the bottom of the spinal cord, control of elimination is almost always impaired. Level of paralysis can generally be determined soon after birth, but sometimes there are changes related to surgery or infection. Although the defect in the skin, which covers the abnormal spinal cord, is repaired early, this does not make the spinal cord function. The defect is repaired to prevent infection and to prolong life.

Most children with spina bifida also have Arnold-Chiari malformation of their brain, in which some structures of the brain are placed abnormally low in the head or even in the neck. This is frequently associated with hydrocephalus, which is the accumulation of too much fluid under too much pressure in the central areas of the brain. Some 90 percent of children with spina bifida have hydrocephalus and need surgical shunting of the fluid through tubes from the head into the abdominal cavity to prevent further brain damage. Some children with hydrocephalus have little or no problem with learning, coordination, and use of their nonparalyzed limbs, but some have severe problems in these areas. This cannot always be completely predicted, but children with extremely large heads or smaller than normal heads tend to have the lowest intelligence. Some children with Arnold-Chiari malformations also have difficulty in control of swallowing and breathing and may need to be fed by tube or have a tube inserted in the windpipe to help them breathe. Many children with

spina bifida have other anatomical defects including curvatures of the spine, malformations of the limbs, malformations of the kidneys, and sometimes more serious problems.

Children and adults with the condition need continuing medical care. Neurosurgical care is needed to make sure that shunts continue to function, and most children with shunts will need to have their shunts revised surgically many times throughout their lives. This generally needs to be done on an emergency basis and cannot be planned. Sometimes complications, related to the Arnold-Chiari malformation or to scarring around the abnormal area of the spinal cord, cause a child to lose function in his arms or more function in his legs. These can frequently be helped with surgery. Orthopedic surgery may be necessary to correct deformities. Physical therapy is almost always necessary to help children strengthen muscles that work and teach them how to stand and walk with braces or how to use a wheelchair, depending on their level of paralysis, how well they can use their hands, how quickly they learn, and what other medical problems they have.

Bladder and bowel care issues are complicated. When a bladder tends to fill up and does not empty completely, urine may back up into the kidneys and cause damage. For this reason, children with spina bifida need to have their bladders and kidneys studied by x-ray frequently throughout their lives. If a child is not able to empty his bladder, he must be catheterized or have a surgical procedure to prevent

the backup of urine. Sometimes a child's bladder will empty continuously so that he is wet all the time. This can be helped with drugs, the use of catheters, and sometimes surgery. The bowels also can either empty continously, causing skin problems, or they can be obstructed. These problems can be helped in various ways, but some problems in continence are likely to remain lifelong issues.

Although most children with spina bifida and hydrocephalus are not retarded, they are generally on the low side of average. They also frequently have learning disabilities—problems with remembering things, remembering the order of certain tasks, making connections between things that are learned, and using the hands without looking directly at them. As is the case with children with cerebral palsy, early learning is impaired because of problems with moving around and difficulties in sitting up. Most of the time, school progress is below normal because of learning disabilities. Usually attainment of self-care is much more difficult than for children who move and feel normally, partly because we are trying to teach many more and more complicated pieces of information to children whose learning is somewhat impaired. Growth brings special problems to children with spina bifida, as they frequently develop curvatures of the spine; because of difficulty with moving around quickly, they frequently become obese, which increases difficulties in walking. It is common for a teenager of average intelligence still to be dependent for much of his care. However, learning continues, and many young adults are able to work and to live independently. People growing up with the condition also need to learn how to handle their medical needs, as they will require involvement with a variety of medical professionals throughout their lives.

No one at this point knows whether the lifespan of a person with spina bifida and normal kidney function will be seriously limited. Certainly all these individuals face a number of surgical procedures and infections throughout their lives, and all of this may create more complications. However, the condition varies considerably, so that some are able to live completely independently, whereas others, because of cognitive problems or severe physical dependence, are not. Women with spina bifida are able to bear children, although they have a higher risk of having a child with the condition, as well as risking many complications of pregnancy. Nearly all men with spina bifida are infertile, and sexual functioning is frequently abnormal, although surgical and medical treatment and counseling may be helpful.

Sensory Handicaps

Sensory handicaps are common major disabilities of childhood. Hearing impairment occurs in one in 600 children and visual impairment in about the same number. Hearing impairment can be hereditary, can be related to prematurity, can be related to infections in the fetus or newborn, or can come from other problems as well. It is

frequently not diagnosed until the child is delayed in speaking. Certain groups of children should have their hearing tested early and frequently because they are known to be at high risk, including children with family histories of hearing impairments, premature infants, and children who have had infections with cytomegalovirus and rubella. Not all children with hearing impairment benefit from aids, but many do. It is important for these children to have speech therapy, early educational counseling with their families, and therapy to learn how to pay attention to the residual sounds they do hear.

Visual impairment also comes from many underlying problems. Sometimes eyes do not develop normally, and sometimes infection interferes with eye function. Many premature babies also have scarring of the back of their eyes. Vision loss is usually diagnosed far sooner than hearing loss, often in the first few months of life, when the child does not respond to the mother's face. Sometimes it can be difficult to differentiate a severely retarded child, who does not understand the significance of what he sees, from a blind child, but this difference usually becomes apparent. Blind children also frequently have delays in sitting, crawling, and walking and in exploring the environment, as they do not know what is in front of them and do not have a sense of distance or of the safety of the environment. For these reasons, they frequently act in a way that is frightening to parents. Early education from a person who is used to working with blind children and has a sense of the normal development of such children is important. When deafness and blindness co-exist, or when either co-exists with brain malformations, mental retardation, or other physical disabilities, problems are magnified. We depend on our intact systems to work around places where there are problems, and if all alternate pathways and experiences are blocked, it is much more difficult for a child to learn about his environment.

SUMMARY

All children with disabilities are different, as are all children considered to be normal. How significantly a person's life is affected by a mental or physical disability, or a sensory loss, depends to a great deal on other factors such as personality, health, education and training offered them, and the support of a family. It is important to remember, though, in the cases of children with biological/physical pathology, love and attention will not "overcome" their abnormalities but will help them do the best they can and have the fullest life possible.

Psychosocial Development

Psychoanalyst Erik Erikson identifies eight stages in the human life cycle, in each of which a new dimension of "social interaction" becomes possible - that is, a new dimension in a person's interaction with himself and with his social environment. Each phase of growth has its strengths as well as its weaknesses. Failures at one stage can be rectified by successes at later stages.

The eight stages of psychosocial development are:

1. Trust vs. mistrust: The infant learns in his first year to trust or mistrust people from the way his needs are met. With this as with all the stages of personality development, the basic issue is not resolved once and for all but arises at each stage of subsequent development.

2. Autonomy vs. doubt: In his second and third year of life, the child takes pride in doing things for himself and can develop a sound sense of autonomy. If rushed, overprotected or shamed, self-doubt will dominate.

3. Initiative vs. guilt: The child age four and five, will leave this stage with his sense of initiative far outbalancing his sense of guilt if he is encouraged at his own level of ability.

4. Industry vs. inferiority: His elementary school experiences as well as his home environment affect his sense of self-worth.

5. Identity vs. role confusion: The search for "who am I;" adolescence.

6. Intimacy vs. isolation: Young adulthood when interpersonal relationshipos -- marriage, friends, productive work -- create a sense of personal identity, a sense of intimacy which, if not established, results in a sense of isolation, of being alone with no one to care for or share with.

7. Generativity vs. self-absorption: Middle age is a time when failure to reach self-actualization leads to self-absorption (an excellent fictional example of sef-absorption is Scrooge in "A Christmas Carol," a story which also shows that unhappy solutions to life's problems can be reversed, i.e., Scrooge becomes generative and gains the sense of intimacy.)

8. Integrity vs. despair: Old age with time for reflection can be a looking back with despair at what might have been or with satisfaction of what was, is, and can be.

KOHLBERG'S MORAL STAGES

(Harvard)

According to Kohlberg in all cultures we find the same forms of moral thinking. There are six forms of thinking and they constitute an invariant sequence of stages in each culture:

Stage 1. Orientation toward punishment and unquestioning deference to superior power. The physical consequences of action regardless of their human meaning or value determine its goodness or badness. Eye-for-Eye morality.

Stage 2. Right action consists of that which instrumentally satisfied one's own needs and occasionally the needs of others. Human relations are viewed in terms like those of the marketplace. Elements of fairness, of reciprocity and equal sharing are present, but they are always interpreted in a physical, pragmatic way. Reciprocity is a matter of "you scratch my back and I'll scratch yours," not of loyalty, gratitude or justice.

Stage 3. Good boy/good girl orientation. Good behavior is that which pleases or helps others and is approved by them. There is much conformity to stereotypical images of what is majority or "natural" behavior. Behavior is often judged by intention - "he means well" becomes important for the first time and is overused, as by Charlie Brown in Peanuts. One seeks approval by being "nice".

Stage 4. Orientation toward authority, fixed rules and the maintenance of the social order. Right behavior consists in doing one's duty, showing respect for authority and maintaining the given social order for its own sake. One earns respect by performing dutifully.

Stage 5. A social-contract orientation, generally with legalistic and utilitarian overtones. Right action tends to be defined in terms of standards which have been critically examined and agreed upon by the whole society. There is a clear awareness of the relativism of personal values and opinions and a corresponding emphasis upon procedural rules for reaching consensus. Aside from what is constitutionally and democratically agreed upon, right or wrong is a matter of personal "values" and "opinion". The result is an emphasis upon the "legal point of view" but with emphasis upon the possibility of changing law in terms of rational considerations of social utility rather than freezing it in the term of Stage 4 "law and order". Outside the legal realm, free agreement and contract are the binding, elements of obligation. This is the "official" morality of the Americal government, and finds its ground in the thought of the writers of the Constitution.

Stage 6. Orientation toward the decisions of conscience and toward self-chosen ethical principals appealing to logical comprehensiveness, universality and consistency. These principles are abstract and ethical (the Golden Rule): they are not concrete moral rules like the Ten Commandments. Instead, they are universal principles of justice, of the reprocity and equality of human rights, and of respect for the dignity of human beings as individual persons.

SEQUENCE OF NORMAL DEVELOPMENT

AGE/MONTH	GROSS MOTOR	FINE MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
Birth to 1 month	-In prone, lifts head to clear nose. -Lifts head when held at shoulder. -Arm, leg and hand movements are all reflexive.	-Reflexively retains rattle placed in hand. -Hands usually held fisted near face.	-Visually tracks bright object to midline. -Responds to sudden or familiar voices. -Reacts to change with more or less body movement.	-Responds to voice. -Makes small throaty noises. -Expresses demands with cries.	-Responds positively to comfort (physical or vocal). -Regards faces and quiets down. -Adjusts posture to body of person holding.	
2 months	-Turns from side to back. -Lifts head consistently in prone. -Legs kick in sequence in supine.	-Regards grasped object. -Hold object for 5-10 secs. before dropping.	-Visually tracks object past midline. -Looks at face when spoken to.	-Responds vocally to voice. -Makes single, short vowel sounds. -Shows anticipatory excitment.	-Smiles at people besides mother. -Shows distress, excitment, delight. -Can quiet self with sucking.	
3 months	-In prone, rests on forearms raising head and chest. -Held in standing, lifts foot and bears some weight. -Sits supported with minimum head bobbing.	-Hands usually open, grasp reflex fading. -Beginning to swipe, but off target. -Reaches for objects with both hands, often misses.	-Looks longer at face than at objects. -Watches movement of own hands. -Repeats hand or leg movement to keep toy in motion.	-Babbles or coos when talked to. -Vocalizations differentiated when stimulated.	-Discriminate mother from others. -Anticipates feeding. -Crying decreases dramatically.	

References: Early LAP, EMI, First Twelve Months of Life by Frank Caplan.

SEQUENCE OF NORMAL DEVELOPMENT

HANDOUT I

AGE/MONTHS	GROSS MOTOR	FINE MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
4 months	-In prone, lifts head to 90° angle. -In supported sitting, head steady but set slightly forward.	-Head & arms symmetrical in midline when in supine. -Hands come to midline when in supine. -Brings object to mouth when placed in hand. -Reaches for object on table when supported in sitting.	-Waves, bangs, shakes & mouths objects. -Visually follows objects. -Glances from one object to another. -Head follows dropped toy & lingers at point of disappearance.	-Makes noises, especially when alone. -Turns head deliberately toward source of sound.	-Indiscriminate attachment to caregivers. -Social smile. -Working on developing sense of trust. -Laughter appears.	
6 months	-Rolls from stomach to back, back to stomach. -Sits briefly by propping forward on extended arms.	-Palmar grasp of cube. -Reaches for & grasps object at midline. -Grasps & holds one block & reaches for another.	-Manually & visually inspects objects. -Repeats hand movements systematically to keep object active. -Notices when toys are gone.	-Enjoys & vocalizes to mirror image. -Initiates making sounds directly at people. -Responds in different ways to friendly & angry tones.	-Shows pleasure, fear, distress, sometimes anger. -Differential social responsiveness.	-Pats or puts hand on bottle. -May push spoon away or help it to mouth.
9 months	-Sits steadily without arm support, 10 min. -Assumes hand/knee position. -Crawls on floor by pulling body with arms. -Placed in standing, holding onto furniture, supports full body weight on feet.	-Radial digital grasps beginning. -Transfers objects from one hand to another. -Crude release of objects. -Accurate unilateral reaching. -Pulls large peg from pegboard.	-Retrieves totally covered object. -Pulls string to retrieve object. -Uprights objects which are presented in reverse. -Finds toy hidden under one of two screens. -Watches adul and imitates adult's actions on objects	-Imitates sounds such as cough, tongue click. -Says mama, dada without specific meaning. -Babbles with a variety of sounds. -Stops when hearing no. -Looks at simple picture, if named.	-Specific attachment, imitation of social games. -Separation & stranger anxiety develops.	-Feeds self cracker, etc. -Begins to hold own bottle.

AGE/MONTHS	GROSS MOTOR	FINE MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
12 months	-Pivots while sitting. -Stands alone momentarily, without support. -Walks with 1 hand held.	-Pincer grasp. -Digital manipulation. -Stabilizes with one hand while manipulates with other. -Releases cube into container. -Builds a tower of 2 blocks.	-Functionally uses familiar objects. -Touches mechanical toy when it ceases. -Puts round form into formboard with demonstration.	-Uses 1-4 words with consistency. -When jargoning, real words appear. -Gives up toy when asked. -Responds to "Where's mommy/daddy?" (by looking at them).	-Multiple attachments begin. -Shows affection. -Interested in other children.	-Holds own bottle well. -May be dry after nap. -Begins to help while being bathed. -Helps put arms into sleeves, legs into pants, foot into sock.
15 months	-Attains standing independently, unsupported. -Walks with stability; able to stop & start, but has difficulty with corners & sudden stops. -Walks, carrying toy. -Creeps upstairs.	-Fist grip on crayon. -Uses fingers to help turn several pages of book. -Smooth accurate reaching. -Lids off/on round boxes. -Throws small ball in general direction of adult.	-Dumps pellet from bottle. -Gives toy to adult to reactivate. -Imitates scribbling. -Seeks adult as causal agent. -Puts round form in hole when hole is pointed out.	-Uses 4-6 words, including names. -Pats correct picture in book (ie. when asked "Where's the doggie?).	-Multiple attachments. -Begins to show moods. -Uses caregiver as base for exploration.	-Finger feeds self part of meal. -Brings spoon to mouth; may turn over before getting to mouth.
18 months	-Walks fast or runs stiffly; walks sideways & backward. -Walks upstairs with 1 hand held. -Creeps backward downstairs.	-Reaches for and grasps objects at arm's length. -Uses fingers to turn 2-3 pages of a book. -Stacks 3-4 blocks.	-Spontaneously scribbles. -Imitates line stroke. -Uses trial and error to solve simple tasks.	-Gradual increase in vocabulary. -Uses real words, less gestures, to indicate wants. -Identifies 1 or more body parts.	-Multiple attachments, better coping with separation. -Pleasure & pride over mastery.	-Uses two hands to lift & hold cup without spilling. -Fills spoon; may use fingers. -Indicates wet pants by crying or patting

AGE/MONTHS	GROSS MOTOR	FINE MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
18 months (Continued)	-Picks up toy & returns to standing without falling. -Steps on ball in an attempt to kick.	-Throws small ball straightening elbow & fingers when standing. -Unzips.	-Attention to 2-dimensional materials. -Places round form in hole with no help.	-Carries out 2 consecutive directions with object (ie. ball).		-Tries to wash hands and/or face. -Takes off simple articles of clothing (hat, socks, mittens).
21 months	-Walks upstairs holding rail, downstairs with hand held - two feet on each step. -Maintains squat for several mins. -Kicks ball independently with demonstration.	-Puts ring on ring stack. -Stacks 5-6 blocks. -Completes square holed pegboard.	-Starts mechanical toy independently. -Imitates vertical & circular strokes. -Uses visual foresight rather than trial & error when solving familiar problems.	-20 word vocabulary. -Imitates some 2-3 word sentences. -Imitates environmental sounds (ie moo, buzz). -Recognizes most common objects & pictures when named.	-Beginning emergence of sense of self. -Sense of separation. -Responsive to other children.	-Handles cup well with two ha.
24 months	-Walks with heel-toe gait. -Runs well, no falling. -Jumps from bottom step, one foot leading.	-Puts simple screw device together. -Puts pop beads together. -Uses fingers to turn one page of book. -Stacks 6-7 blocks. -Zips.	-Does not attempt to stack a solid ring mixed among other rings. -Matches 2 basic colors. -Begins to use visual foresight in solving unfamiliar problems. -Completes 3-part formboard.	-Uses 2-3 word sentences. -Refers to self by name. -Follows 1 command involving a preposition (ie. put the ball <u>in</u> box). -Recognizes 5 body parts.	-Task is to develop a sense of autonomy. -Defiance, ambivalence. -Beginning to role play.	-Holds glass with one hand. -Fills spoon without fingers, brings to mouth without turning.
30 months	-Walks on tiptoes after demonstration. -Jumps from 12" with one foot leading. -Jumps up & down in place with both feet together.	-Digital grasp of crayon. -Snips with scissors. -Initiates activities with one hand, uses other to assist.	-Imitates horizontal & vertical strokes. -Adds chimney to block train. -Selects one basic color correctly when asked "give me the ___one."	-Uses pronouns (not always correctly). -Beginning to use plurals. -Chooses <u>big</u> & <u>little</u> item from group of several big & little items.	-Interest in peers. -Role play. -Parallel play.	-Begins to use napkin. -Asks to go to potty. -Helps while being bathed. -Takes off pants. -Tries to undress self

AGE/MONTHS	GROSS MOTOR	FINE MOTOR	COGNITIVE/ACTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
30 months (Continued)		-Strings large beads. -Unscrews lids. -Stacks 8 blocks -Throws small ball 5-7 feet.	-Gives 1 when asked "give me one block." -Matches basic shapes in a shape box.	-Selects 3 pictures of action words.		
36 months	-Balances on one foot independently for one second. -Runs smoothly on tiptoe. -Jumps from bottom step with both feet together. -Walks upstairs & downstairs without rail, two feet on each step. -Rides tricycle.	-Holds crayon with adult-type grasp. -Cuts straight across sheet of paper. -Strings small beads. -Hammers a peg toy. -Stacks 9-10 blocks. -Catches large ball. -Unbuttons large buttons.	-Imitates a cross. -Copies circle. -Classifies objects. -Nests 4 cups. -Imitates 3-cube bridge. -Aware picture is upside-down. -Names 1 color correctly. -Matches 3/4 colors. -Gives 2 when asked "give me 2 blocks."	-Tells about recent experiences. -Knows a few rhymes or songs. -Follows commands involving 3 or more prepositions. -Understands many common adjectives.	-Marked increase in peer orientation. -Parallel play. -Associative play. -Gender identity usually established. -Dramatic play.	-Feeds self with little spilling. -Few toileting accidents. -Begins to help blow nose. -Tries to comb hair. -Puts on shoes (not always correctly). -Laces incorrectly.
48 months	-Balances on one foot 4-8 secs. -Walks a balance beam, stepping off 1-2 times. -Hops on 1 foot 2-3 times. -Walks upstairs without rail, downstairs with rail, alternating feet.	-Better coordination of preferred hand. -Folds & creases paper 3 times with demonstration. -Cuts out circle. -Buttons. -Fastens snaps.	-Imitates square. -Copies square, although cornerless. -Copies circle. -Copies cross. -Names 3 colors correctly. -Puts together interlocking 3-piece puzzle. -Counts 3 objects with pointing.	-Emergence of most grammatical elements. -Understands concept of "today," "yesterday", "tomorrow." -Understands most verbs. -Asks questions (i.e., who, why). -Uses future tense. -Uses negative. -Uses prepositions	-Peer oriented. -Leading and following. -Affection & hostility towards peers. -Task is to develop strong sense of initiative. -Many fantasy fears. -Thematic dramatic play.	-Begins to use fork. -Wipes self with assistance. -Washes & dries hands & face. -Brushes teeth. -Undresses with minimal supervision. -Laces shoes. -Begins to distinguish front & back of clothes.

AGE/MONTHS	GROSS MOTOR	FINE MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
48 months (Continued)				-Uses past tense correctly.	-Associative, some cooperative play.	
60 months	-Walks up & down stairs without support, alternating feet. -Balances on one foot indefinitely. -Skips with alternating feet. -Running broad jump 2-3 feet. -Walks on balance beam without stepping off.	-Catches large ball bounced to him/her. -Ties simple bow.	-Copies square. -Copies triangle. -Traces diamond. -Names 5 colors correctly. -Letter & number reversals common. -Begins to identify secondary colors. -Counts 10 objects with pointing.	-Gives descriptive comments while naming pictures. -Uses 4-8 word sentences. -Tells familiar story. -Describes objects. -Asks meaning of words.	-Increasing cooperative play. -Many real fears. -Frequent nightmares. -Often low frustration tolerance & anxiety about mistakes. -Dramatic play.	-Cuts with knife. -Uses straw effectively. -Full independence in toileting. -Blows nose independently. -Combs hair. -Washes self in bath.
72 months	-Hops well. -Standing broad jump 2-3 feet. -Jumps with two feet over raised rope.	-Catches ball with one hand. -Cuts on a straight line without deviating.	-Names 6 colors correctly. -Adds within 5 (i.e. 2+3, 4+1) -Puts together 12-piece puzzle.	-Mastery of most speech sounds & grammatical rules. -Understands concept of future.	-Task is mastery of real world. -Loosely organized group play with attempts to follow rules.	

INTERRELATED EFFECTS OF PROBLEMS IN DEVELOPMENTAL AREAS

Handout II

	GROSS MOTOR	FINE MOTOR	PERCEPTUAL-MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
Gross Motor effects.....		-Inadequate head & trunk control may limit fine motor manipulation & visually directed reaching. -Inability to prop in prone, maintain 4-point, & crawl may reduce scapular stability -Difficulty sitting may limit bilateral manipulation of objects.	-Reduced sensorimotor experience of normal movement may limit body awareness. -Difficulty moving & exploring environment may hinder development of space perception.	-Inadequate head & trunk control & resulting lack of fine motor manipulation may limit cognitive growth gained thru exploring & acting on objects. -Difficulty moving & exploring environment may limit learning opportunities.	-Inadequate head & trunk control may interfere with coordination of respiration & phonation required for speech. -Inability to move in & explore environment may delay development of labels for spatial concepts & actions.	-Inability to move independently of caregiver may hinder establishment of separate identity & independence. -Immobility may limit play opportunities & social interaction; may reduce access to many buildings. -Awareness of physical inadequacy may interfere with self-concept & successful social interaction.	-Inadequate head & trunk control, stability & equilibrium in sitting may hinder development of feeding, dressing toileting, & hygiene skills.
Fine Motor effects.....			-Inability to adequately explore environment may limit ability to gain information about objects through the senses.	-Difficulty manipulating objects in environment may limit learning opportunities. -Difficulty manipulating objects may hinder ability to demonstrate cognitive skills.	-Inadequate hand function may limit use of some communication aids (braille, signing, typing, communication board). -Inadequate fine motor control may hinder development of writing. -Inability to explore objects in environment may delay development of labels for objects.	-Inability to interact with toys may hinder play with peers. -Inability to interact with toys may result in frustration, resulting in poorly developed self-image.	-Difficulty with upper extremity control may hinder ability to manipulate feeding utensils, & may hinder development of dressing, toileting & hygiene skills.

INTERRELATED EFFECTS OF PROBLEMS IN DEVELOPMENTAL AREAS, Handout II

	GROSS MOTOR	FINE MOTOR	PERCEPTUAL-MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
Perceptual-motor effects.....	-Inadequate perception of gravity & space may interfere with execution of smooth coordinated movements. -Inadequate body concept may interfere with acquisition of skilled motor activity.	-Inadequate tactile kinesthetic, &/or proprioceptive feedback regarding movements & position may interfere with acquisition or refinement of skills. -Inadequate perception of spatial relationships may interfere with execution of coordinated movements during reaching, placement, & manipulatory tasks.		-Inconstancy of perception information may limit cognitive growth, & hinder ability to respond to surrounding events. -Difficulty making sensory discriminations may lead to inaccurate or inefficient problem-solving.		-Oversensitivity to a particular stimuli may cause behavioral problems.	-Inadequate body concept may hinder ability to manipulate limbs & garments during dressing/undressing. -Inadequate tactile/kinesthetic functioning may hinder ability to manipulate garment fastenings.
Cognitive/ Adaptive effects.....	-Overall delay in learning skills may affect rate at which motor skills are acquired. -Lowered capacity for applying learned motor skills may hinder generalization of appropriate motor responses.	-Overall delay in learning skills may affect rate at which fine motor skills are acquired. -Difficulty determining alternative strategies for problem-solving may result when confronted with difficult fine motor tasks. -Lowered interest in self-directed experimentation with materials may hinder development of adequate visual-motor coordination.	-Heavy reliance on trial & error approach to learning may result in inefficient motor planning skills. -Reduced number of problem-solving strategies with tasks involving position & movement may limit effectiveness.		-Overall delay in learning skills may affect rate at which communication skills are acquired. -Heavy reliance on concrete experiences to understand abstract ideas may hinder acquisition of language concepts. -Lowered capacity for applying learned language concepts may hinder generalization of responses.	-Heavy reliance on concrete experiences to understand abstract concepts may hinder interpretation of social cues. -Lowered interest in self-directed play may hinder development of adequate play skills. -Reduced number of problem-solving strategies when faced with social problems may hinder effectiveness. -Lowered capacity for applying learned social skills may hinder generalization of responses.	-Overall delay in learning skills may affect rate at which self-help skills are acquired. -Lowered capacity for applying learned self-help skills may hinder generalization of responses.

INTERRELATED EFFECTS OF PROBLEMS IN DEVELOPMENTAL AREAS, Handout II

	GROSS MOTOR	FINE MOTOR	PERCEPTUAL-MOTOR	COGNITIVE/ADAPTIVE	COMMUNICATION	SOCIALIZATION	SELF-HELP
Communication effects.....	-Inadequate comprehension may interfere with ability to demonstrate motor skills upon verbal request.	-Inadequate comprehension may interfere with ability to demonstrate manipulative skills upon verbal request.		-Inadequate comprehension may interfere with ability to demonstrate cognitive skills upon verbal request. -Expressive language &/or oral-motor problems may interfere with ability to verbally demonstrate knowledge of abstract concepts.		-Difficulty conveying thoughts & feelings may affect peer relationships, cause frustration, or emerge as inappropriate physical self-expression. -Reliance on demonstration as way to understand rules for social games may disrupt group activities.	-Inadequate comprehension may interfere with ability to demonstrate self-help skills upon verbal request. -Inadequate oral-motor skills may hinder development of independent feeding.
Socialization effects.....	-Extreme passivity may result in fear of exploration of new environment. -Impulsive behavior may result in poorly graded movements; short attention span may result in difficulty learning sequence of movements.	-Extreme passivity may result in limited manipulatory skills. -Impulsive behavior may result in poorly graded movements; short attention span may result in difficulty learning sequence of movements.	-Extreme passivity may reduce amount of stimuli received, thus limiting information gained from the environment.	-Extreme passivity may reduce exploration of objects & self-directed problem-solving. -Impulsive behavior may result in ineffective, unsystematic problem-solving; short attention span may reduce the number of strategies attempted when problem-solving.	-Extreme passivity may reduce amount of early vocal exploration & later self-initiated conversation. -Impulsive behavior may result in inefficient listening skills & difficulty following verbal directions.		-Extreme passivity may result in reliance on adult assistance. -Impulsive behavior may result in poorly graded movements; short attention span may result in difficulty learning sequence of movements.
Self-help effects.....						-Inability to meet self-help needs may result in poorly developed self-image. -Dependence on family members to take care of basic needs may create stress within family. -Inadequate self-help skills may prevent participation in social, educational, and vocational events.	

Stages in Development of Infants

Several researchers concluded that there is evidence from a number of behaviors in infancy, such as stranger reaction and object permanence as well as the way an infant uses toys, for stages of development. By stages they mean that the infant behaves very differently at one age than he does later or earlier, and that you can predict how an infant will behave, or what stage he is in, by his age. The stages they discussed are as follows, and they fit well with Piaget's stages.

Stage 1 (around 0-2 months) Self-contained

The infant responds mostly to events happening inside her own body. She begins to be involved in the world as she pays attention to visual and auditory stimuli.

Stage 2 (around 2-7 months) Subjectivity

The infant begins to explore actively but knows about the world only through her own actions. She doesn't yet know that she is separate from her toys or from other people. As she gets feedback from her actions (responsive toys, responsive people), this realization begins.

Stage 3 (around 7-13 months) Separation of means from ends

During this stage the infant comes to see herself as separate and different from objects and the rest of the world, and able to make things happen. Reaction to strangers and object permanence are part of this development.

Stage 4 (around 13-18 months) Entity-entity relationships

During this stage the infant comes to understand that two objects in the environment can be related without the infant being involved with either one. So she can understand, for instance, that pegs and a pegboard go together without having to try them first. It becomes possible to connect a name with an object in the same way.

Stage 5 (around 18-30 months) Symbolic relations

By this stage the infant is beginning to use symbols (many of which are words) and to understand that relationships between things in the environment can be complex. So, for example, she is able to say "Baby go night-night" and use the words in her mind as a symbol for an earlier or later activity which she observes or is just told about.

The researchers conclude that changes from one stage to another result from changes in brain organization due to a comination of brain development with life experiences. As such, these stages should occur in all infants to some extent. Clues to what stage an infant you are working with can be gotten from the way the infant plays. In Stage 1 the infant plays with objects little though she may look at them. In Stage 2 she plays but it doesn't matter much with what. She tends to do repetitive things like banging, shaking the toy, with any toy. By Stage 3 she is beginning to know that objects are different from one another and can be used to do different things. You may see her crumple, stretch, drop, pat, shake, etc. depending on the nature of the object. By Stage 4 she is beginning to combine objects, putting things into things, beginning to understand puzzles, pegboards, stacking objects, and so on. She also begins to know that objects can have names and begins to communicate, as with pointing. By Stage 5, she can imitate several activities one after another, begins to show fantasy play such as with a doll, and begins to use language as symbols for actions with simple sentences.

Massachusetts Hospital School

PROJECT ACCESS WORLD

PROJECT ACCESS WORLD was established by the Massachusetts Hospital School in 1987 as an outreach effort to provide a regional service-delivery mechanism for children with physical disabilities to receive customized adaptations and equipment devices usually not available commercially. The program focuses on needs which usually fall in the areas of mobility, self-care, communication, socialization and recreation. This innovative approach is based on the realization that many children with severe physical disabilities are being mainstreamed into public schools where they encounter obstacles to learning, socialization with peers and recreation. Children either lack equipment which affords independent participation or are faced with personnel who are uninformed of the existence and use of current technological and adapted special equipment which would enhance their participation in a learning situation. At present, a significant portion of the disabled pediatric population requires specially designed equipment and access to current technological innovations to ensure optimal functioning at home, at school, and at the first work-site.

ACCESS WORLD is housed on the grounds of the Massachusetts Hospital School. Functioning in a workshop setting, the program encompasses an interdisciplinary rehabilitation team of professionals who evaluate the environmental and personal needs of each child who is referred to the Program on an outpatient basis. The team, working with a fabricator and rehabilitative engineer, designs and manufactures a coordinated, customized system of equipment for each child referred. All ACCESS WORLD products are structured to eliminate barriers and optimize a child's independence and functional abilities.

Once the equipment is complete, therapists provide individualized training on equipment use, both on and off campus, working with child, parent, school, and employers, if needed.

As a one-stop regional center for disabled youth, ACCESS WORLD promotes less travel for families, reasonable time-frames for the fabrication of equipment, and individual training. ACCESS WORLD is a comprehensive model that ultimately will allow disabled children to remain in their natural settings without hospitalization.

The project is financially supported by the combined efforts of private foundations and the Department of Public Health.

DIGESTIVE SYSTEM: FEEDING AND NUTRITION

Objectives

After completing this unit, participants will:

1. Name four parts of the gastro-intestinal system and their functions.

2. Discuss three disorders of this system and their treatment/care.

3. Demonstrate familiarity with several commonly observed feeding difficulties and appropriate interventions.

4. Outline three special diets and the conditions for which they are appropriate.

5. Demonstrate knowledge of the appropriate amounts of food to feed a particular child.

6. Demonstrate a working knowledge of proper positioning for feeding.

ANATOMY

The digestive system is responsible for breaking down food into a form which can be transported by the blood to all parts of the body. This action is both mechanical and chemical. The digestive tract is 30 feet long; each organ is important to the end goal of delivering supporting nutrients to the body cells.

Mouth

- Teeth shred and tear large chunks of food into smaller pieces.
- Enzymes in the saliva start to dissolve some carbohydrates. Enzymes are made by the body to help transform one substance into another to speed digestion; otherwise digestion would take days instead of hours.

Esophagus

- Moves food to stomach

Stomach

- Churns, mixes and dissolves food

Liver

- Manufactures bile
- Stores glucose, a form of sugar which is released in large amounts when needed by the body

Gall bladder

- Stores bile

Pancreas

- Secretes pancreatic juice

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Small intestine

- Digestive juices from liver, gall bladder and pancreas break down food in the duodenum, the first part of the small intestine
- Villi lining the duodenum absorb digested food which is moved by the bloodstream to the cells

Large intestine

- Water is reabsorbed into the body

Rectum

- Collects waste
- Expels waste when it is full by relaxing sphincter muscle

Anus

- Opening to outside of body

DISORDERS

Oral Cavity Conditions

Cleft Lip and Cleft Palate

The incidence of cleft lip or cleft palate is from one in 600 to one in 1250 births. A cleft defect may occur without any other disability or medical condition. There appears, however, to be an increased incidence of congenital and intellectual impairments among children with cleft defects. This can be partially explained by an increase in hearing impairment in children with cleft palate and by the frequency of cleft defects among children with chromosomal abnormalities.

Immediate concerns

The feeding of an infant born with a cleft defect must be carefully managed to avoid aspiration (inhaling food or liquid) and infection.

- Feed in an upright position.
- Use softened nipples with slightly enlarged openings.

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- Use a medicine dropper or feed by gavage tube at times.

A complete program of habilitation may require years of special medical, surgical, dental and speech treatment.

Surgical correction

Cleft lip: usually done a month or two after the infant is gaining weight and is free of infection.

Cleft palate: optimally performed from six months to five years of age, depending on the need to take advantage of palatal changes which occur with growth.

Final surgeries to bring about optimal cosmetic results may not be performed until adolescence.

Management and Care

After surgery:

1. Gentle suction of the nasopharynx minimizes the chances of collapse or inflammation of the lung. A bulb syringe may be sufficient.
2. Maintain clean suture line.
3. Prevent strain on the sutures.
   a. Feed with a medicine dropper or spoon.
   b. Restrain arms with elbow cuffs for three weeks.

Ongoing:

1. Feeding techniques will be different for a cleft lip than for a cleft palate.
2. Unnecessary exposure to colds and flu should be avoided. Modifications in environment (e.g., increased humidity in classroom) are preferable to limiting experiences.

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3. Both parents and child need to have professional help in dealing with the emotional impact of the disability.
4. A team approach is best, and may require the services of pediatrician, plastic surgeon, otolaryngologist, psychologist, orthodontist, speech therapist and social worker.

Oral Moniliasis (Thrush)

Oral infection with the fungus Candida albicans is fairly common in the newborn infant. The oral lesions are white, flaky plaques covering all or part of the tongue, lips and gums. Discomfort may interfere with eating. The usual and simplest form of treatment is applying nystatin liquid, four times a day, to the insides of the cheeks to ensure maximum contact with the thrush. Thrush may occur whenever a child is chronically ill or malnourished; it is one of the primary symptoms of pediatric AIDS.

Esophageal Defects

The most common congenital defects of the esophagus are atresia (absence of the normal opening) and fistula (an opening where there shouldn't be one). Most of these malformations can be corrected surgically. Success is dependent on early diagnosis before bronchopneumonia or dehydration develops. Common warning signs that something may be wrong with the esophagus are:

- excessive salivation and drooling
- choking
- cyanosis (bluish skin due to lack of oxygen)
- regurgitation of feedings

The most common cause of acquired esophageal stricture or narrowing is the ingestion of a corrosive chemical, such as a household cleaning agent. The first mouthful causes intense burning and pain which stops further swallowing, but the damage has already occurred.

Treatment

- Ampicillin
- Dilation of the esophagus, with gradual increase in the size of the dilators
- Instrumentation is avoided in severe acid burns; jejunostomy (opening made in intestinal wall) may be necessary for feeding purposes
- Surgery may be necessary to replace the esophagus

Gastrostomy

When X-ray studies confirm the diagnosis of an esophagus which does not function properly, a gastrostomy may be performed. A gastrostomy is the procedure by which an opening is made through the abdominal wall so that the child may receive feedings directly into the stomach. An upright position is maintained during these tube feedings to avoid backup of stomach contents (gastro-intestinal reflux).

Many children who need to be fed by gavage (via the esophagus), jejunostomy or gastrostomy tubes may eventually be weaned off these feedings and helped to gradually increase their feedings by mouth. Patience is the prime ingredient in this process. The child's mouth may need to be desensitized; perseverence is needed because each feeding will take longer than usual at first.

Liver Disease

Infectious Hepatitis

This is the leading viral disease in the United States for which no vaccine exists. Life-threatening complications are:

- hemorrhage

fluid retention

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Treatment

- Diet of adequate calories; frequent feedings
- Steroids to improve appetite, decrease inflammation and improve kidney function
- Prednisone is used only for coma, fever, bleeding and abnormal blood chemicals

Chronic Liver Disease

In children, chronic liver disease may be part of a wide variety of disorders which may be acquired or hereditary. Primary hereditary metabolic disorders include:

- Wilson's Disease
- Cystic Fibrosis
- Sickle Cell Disease

Children with chronic liver disease are jaundiced; their skin and the whites of their eyes may be yellow. Fluid in their abdomens may need to be drained and bleeding may occur from the esophagus, so that they need transfusions.

Pancreatic Disease

Cystic Fibrosis

In this country, Cystic Fibrosis accounts for the great majority of cases of progressive pulmonary (lung) disease in children. It is a hereditary, recessive disorder due to a generalized dysfunction of glands. About 5% of the population in predominantly Caucasian countries are carriers, making Cystic Fibrosis the most common lethal hereditary disease among young Caucasians.

Mucus-producing glands swollen or inflamed by abnormal secretions may cause:

- pancreatic lesions
- liver fibrosis
- gallbladder disease
- lung disease
- cardiac abnormalities
- infertility

Management and care

Until the basic defect in Cystic Fibrosis is discovered, an effective treatment or cure cannot be devised. At present, therapy is mainly aimed at slowing down or preventing complications. A multi-disciplinary team approach is needed, involving pediatrician, physical therapist, social worker, dietitian, and at times, psychiatrist.

Therapeutic measures include:

- Respiratory therapy
  - inhalation therapy
  - postural drainage
- Antibiotics to control infection
- Vitamins
- Drugs
  - steroids
  - digitalis
  - bronchodilators
  - pancreatic enzymes
  - diet modifications

Children with Cystic Fibrosis may enjoy full normal activity or become so disabled that they are confined to bed or chair. The extent to which pulmonary and digestive systems are affected usually determines the child's degree of function.

Disorders of the small and large intestine, rectum and anus

A variety of congenital anomalies of the digestive tract may be responsible for:

- lack of nerve control (e.g., Hirschprung Disease)
- obstruction
- inflammation

These conditions may require the construction of an artificial opening, called a stoma, into the intestine through the abdominal wall.

Colostomy and ileostomy

A colostomy is the diversion of the large intestine or colon so that bowel contents are collected outside the body, usually into a disposable plastic bag, held in place against the abdomen by self-sticking adhesive or a belt. The semi-solid stool collected this way is not irritating to the skin.

When the lower part of the small intestine, the ileum, is diverted, the intestinal contents are liquid. If a child has an ileostomy, the irritating qualities of the liquid demand that meticulous skin care be maintained. Most colostomies in young children are temporary; the bowel is reconstructed after a few months or years.

Management

- diet with enough fiber to ensure stool formation
- plenty of fluids
- meticulous skin care
- control of odor and/or gas through diet and frequent change of appliance
- encourage involvement of child in self care
- no physical limitations are necessary

Danger signs which should be reported

- watery diarrhea, which can progress rapidly if not checked
- large amount of bleeding through the stoma
- lack of bowel movement
- stomach bloating, pain, vomiting or fever

Source: Medical Aspects of Developmental Disabilities in Children Birth to Three. James A. Blackman, M.D., University of Iowa, 1983.

Encopresis

Encopresis, the involuntary passage of feces which is unrelated to an organic defect or illness, may be present at birth or arise after the child attains bowel control. Since the natural course of encopresis, like enuresis (involuntary passage of urine), may become habit if not resolved, careful neurological, psychological and child psychiatric consultations are indicated. Unless severe psychosocial disorder exists in the family, the problem of encopresis is frequently resolved.

Failure to Thrive

The diagnosis of Failure to Thrive is made when a child (1) fails to grow or (2) has an interrupted growth pattern. The normal growth pattern for the first 2 1/2 years is:

- newborn: weighs at least 5 1/2 lbs. (average is 7 to 7 1/2 lbs.)
- first few days of life: 10% loss of weight
- at six months: doubles birth weight
- at one year: triples birth weight
- at 2 1/2 years: quadruples birth weight

Non-organic FTT

When a child fails to grow without evidence of an organic defect or illness, one needs to examine the parent-child relationship. If the child is not receiving emotional nurturance from at least one parenting person, he or she will exhibit the following symptoms:

- failure to make emotional bonds
- poor appetite
- lack of social responsiveness
- growth failure
- lack of visual tracking and visual reciprocity

Severe symptoms may include:

- poor muscle tone
- complete lack of interest in environment
- serious developmental delay
- death

A diagnosis is confirmed if the child's growth catches up when the child is placed in a nurturing environment and fed sufficiently.

Organic FTT

Although disabled children are vulnerable to non-organic R.A.D. (Reactive Attachment Disorder) and a careful evaluation of all factors in the child's life needs to take place, children may also fail to grow as a result of:

- genetic conditions
- malnutrition before or after birth due to lack of food in general or lack of certain nutrients. If a child is malnourished, weight suffers more than height.
- intoxication, such as lead poisoning
- infestation, such as parasites
- infection, such as tuberculosis or urinary tract infection
- defect in the major organ systems, such as:
  - neurological disorders, brain damage, lack of oxygen or tumor
  - heart defects, which can interfere with the supply of oxygen and nutrients carried by the blood
  - obstruction of the digestive tract, which can cause vomiting and poor absorption of food
  - obstruction of the genito-urinary system, which may cause changes in the electrolytes surrounding the growing cells

FEEDING

Introduction

Feeding is an integral part of life; we, as adults, partake in the ritual of eating at least three times a day and sometimes more. Children, especially infants, eat on a more frequent basis. The required caloric intake for normal weight gain and general development is the greatest per kilogram of weight when a child is born (approximately 115 calories per kilogram weight for the first six months), gradually decreasing as the child grows (82 calories per kilogram weight at 7 - 10 years).

Because eating is such an important part of our lives, it is not difficult to understand why we will put such an emphasis on the development of normal feeding patterns and behaviors in this chapter.

Social/cognitive development begins with the feeding process -- from nurturing and bonding to proper social skills. In this chapter, the goal will be to increase your ability to understand and be sensitive to that bonding/nurturing process, and how it relates to feeding. It is also the intent of this section to increase your awareness of the social implications of feeding problems.

Finally, basic feeding techniques to assist with the feeding process will be discussed and specialized adaptive equipment will be reviewed.

Nurturing and Bonding as They Relate to the Feeding Process

Although there are many causes of feeding problems, the effects are very similar. For the neurologically impaired infant, the most common cause of feeding problems is impairment of the swallowing mechanism with less common problems being congenital malformation of the mouth and throat.

For the premature infant, a common cause of feeding problems is the infant's adjustment to the environment after being taken out of the intensive care incubator. Most premature infants are initially tube fed then slowly transferred over to feedings by mouth. This isn't always easy or spontaneous. Some infants need special stimulation to begin sucking, and it can be very difficult for young parents to understand this problem. Sometimes they see themselves as unable to feed their child, or feel they are being rejected by their new baby. It is important that the child and the parents receive help from the nursery staff to alleviate this problem before the infant is discharged home.

For the first few weeks of life, the child's primary activities are sleeping and eating. It is during these feeding times that the bonding between mother and child begins. It is this early attachment that lays the groundwork for later emotional development. If this early time is interrupted due to severe feeding problems or parent's inability to feed their child, then this bonding is also interrupted.

During the feeding sessions, social responses are also developed. The infant begins to develop attention span and concentration. The closeness of feeding helps the child to concentrate on one stimulus, gradually expanding to exploring the surrounding environment. The child begins to get a sense that he or she can explore the environment knowing that the mother will still be there. Having a secure base helps the child begin to develop confidence.

ORAL MOTOR DEVELOPMENT

Oral Motor Reflexes

All newborns are born with a variety of automatic movements or reflexes. This is true for the oral area as well. While there are many such reflexes, the most common are as follows:

Rooting Reflex:	Turning head (possibly trunk) in direction of stimuli in response to light stroking beside mouth. *Should be gone by three months.
Bite Reflex:	Firm bite in response to stimulation of gums. *Should be gone by 6 - 8 months.
Suckle/Swallow:	Rhythmic pattern to sucking and automatic swallowing in response to food. *Reflex diminishes around 2 - 4 months.
Gag Reflex:	Sudden closing of throat to force out an object, in response to stimulation of base of tongue or throat. *At birth, decreases around 7 months as chewing develops but remains throughout life.

Oral Motor Development

Development is usually spontaneous and emerges in sequence. Although the exact month or day when a particular stage is reached can overlap or vary, the order is usually as follows:

1 MONTH:	poor lip closure -- liquids run out corner of mouth
	bite reflex
	gag reflex -- overly sensitive
	poor head control/just developing
	suckle/swallow reflex
	rooting reflex
3 MONTHS:	beginning head control
	pre-language sounds
	acceptance of strained foods and spoon
	increased movement of tongue for swallowing
	slight gagging
4 MONTHS:	beginning hand-to-mouth coordination/activity
	better lip closure
	increased tongue control
	increased acceptance of textured foods -- may see some increased gagging until mouth adjusts
5 MONTHS:	increased mouthing and oral sensitivity
	increased hand-to-mouth activity/coordination
	teething -- may see increase in drooling
6 MONTHS:	good lip control
	voluntary sucking
	beginning to drink from cup
	beginning lateral tongue movements

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8 MONTHS:	beginning rotary chewing
	beginning finger feeding
	biting and chewing toys
12 MONTHS:	good tongue lateralization
	good jaw movements and control
	good lip control for cup drinking
	fully developed chewing using teeth and elevating tongue
24 MONTHS:	automatic rotary chewing
2 years	holds cup in one hand, spilling decreases
	apt to dawdle and play with food, stir and refuse it
36 MONTHS:	feeds self, rarely needs assistance
3 years	pours from pitcher -- no spilling
	uses fork
	holds utensils with palm up
	interest in setting table
	may get up from table
	either talks or eats
4 YEARS:	rarely gets up from table
	eats and talks simultaneously
	likes to serve self

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5 YEARS: bigger appetite
tends to squirm and monopolize conversation
beginning to use knife
refinement of feeding skills

6 YEARS: uses back of hand to wipe mouth
permanent teeth coming in
prefers fork to spoon

8 YEARS: may cut meat with knife

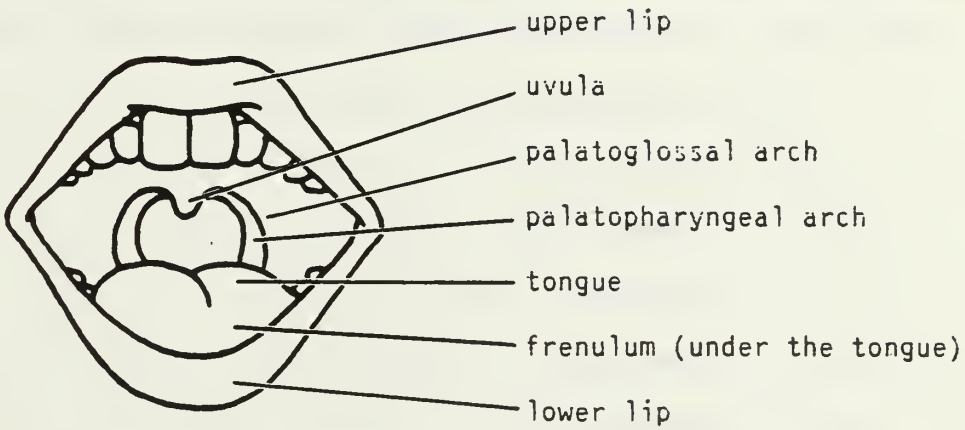
The Relationship between Speech and Feeding

There is a close relationship between feeding and speech development. As oral motor control develops, becoming strong and more manipulative, the infant will begin to make sounds and babble. Chewing gives an opportunity to practice coordinating the movements of the tongue, teeth, and cheeks.

As the child accepts more textured food, the tongue is forced to become more agile, learning to move more rapidly from side to side and front to back. As the child's feeding ability improves, he or she begins rehearsing the oral motor movements for speech. At approximately 6 to 8 months, the child begins to have good lip closure around the spoon. This lip action resembles the movements necessary for the "p," "b" and "m" sounds which will come later on. Sucking and swallowing forces the tongue into an upward and downward motion which propels the food from the front of the mouth to the rear. This type of tongue movement is rehearsing the throaty sounds "ah" and "ga" which are the first speech sounds the child will make.

Oral Structure

Knowing the oral motor area is important especially when feeding a physically handicapped child because stimulation to any or all of these areas may cause an unwanted reaction. The mouth has many structures. The most commonly referred to are:



ORAL MOTOR PROBLEMS

Most feeding problems of a handicapped child stem from some kind of central nervous system dysfunction, though some are behaviorally based. Problems can include abnormal muscle tone, abnormal reflex development or hypersensitive responses to various external stimuli.

Hypersensitivity of the Central Nervous System

Hypersensitivity can affect any of the body's sensory systems:

touch/tactile

pain

temperature

vision

hearing

smell

The most common senses to be hypersensitive are touch/tactile and hearing.

Hypersensitivity to Touch/Tactile Stimulation

Hypersensitivity to touch/tactile stimulation can be seen throughout the total body, just around the face, or just in the mouth. Obvious reactions to tactile stimuli include withdrawing from the source with unusual speed and intensity or becoming exceptionally agitated.

Normal Development of the Tactile System

- Initially, overall physical contact with environment may be either pleasurable or irritating and will usually alternate between the two.
- Early startle is the child's innate reaction to potential dangers and is a protective reflex.

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- As the child becomes accustomed to various stimuli, response diminishes to a less violent reaction. At the same time, the child is also gaining control over the primitive protective reflexes.

Abnormal Development of the Tactile System

Negative response to stimuli does not diminish. If the child's mouth is hypersensitive to touch, it may lead to feeding difficulties. He or she may react negatively to the presentation of spoon or cup, and may also be sensitive to the different textures of food. Severe hypersensitivity may cause intense reactions to variations in food temperature and taste.

Hypersensitivity to tactile stimulation is more often seen in children with increased muscle tone (i.e., cerebral palsy, spastic variety, both quadriplegic and hemiplegic). When handling a child with tactile hypersensitivity, it is best to used a firm touch rather than light stroking. It is also suggested that you avoid over-stimulation and/or activity at all times but particularly right before the meal.

As in most things, there is an opposite end to the spectrum. Some children may be hyposensitive to touch, meaning that they do not fully feel or understand the tactile stimulation coming into their bodies. This is seen most commonly in infants with decreased muscle tone, such as babies with Down syndrome. Safety is the primary concern for these infants because their reflexes may be reduced, increasing the possibility of choking on food or liquids.

Hypersensitivity to auditory stimulation may also be seen in the handicapped child. The child may be startled by what would seem to us to be noise of a "normal" volume.

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This type of response to noise is commonly seen in children with increased muscle tone (cerebral palsy).

Abnormal Muscle Tone

Overall muscle tone is also reflected in the oral-facial musculature. If the child has increased tone, there may be overall tightness in and around the mouth. For the hemiplegic child (abnormal muscle tone only on one side of the body) there may be facial asymmetry. Children with athetoid cerebral palsy or ataxia will display unstable, irregular movements when opening and closing their mouths.

When a child has overall spasticity, there are several commonly seen oral motor problems. One is a retracted upper lip, which makes it impossible for the child to actively remove food from the spoon. Parents tend to scrape the spoon against the upper teeth to remove food, sometimes stimulating oral reflexes in a child hypersensitive to touch. Athetoid children can open and close their mouths, but have difficulty maintaining the mid-open position necessary for cup drinking. The jaw may also deviate from the midline, causing inadequate chewing and lip closure for sucking and swallowing.

Another problem often associated with increased tone is abnormal tongue thrusting, usually seen during swallowing. Upper jaw and tooth alignment deformities may result from prolonged tongue thrusting.

Children with increased muscle tone often have problems developing adequate breathing patterns (this can be a concern, especially if the gag and cough reflex are depressed).

- Increased extensor muscle tone tightly retracts the abdominal muscles, causing shallow breathing.

- Increased flexor muscle tone pulls arms tight over the chest, also causing shallow breathing.

The early developmental reflexes are also often maintained in the child with increased muscle tone. It is important to be aware of these reflexes, what triggers them and how to avoid them. These reflexes can alter the muscle tone, disrupting sitting balance and making the child feel very unstable.

The best way to avoid stimulating these reflexes is to:

- Make sure that the child is relaxed, either through quiet activities or muscle relaxation activities.

- Keep the child's head, trunk and limbs aligned.

- Keep the child slightly flexed at the hips, and make sure he/she has firm support for his/her back and feet.

GENERAL SUGGESTIONS TO HELP NORMALIZE THE FEEDING PROCESS

When feeding a child for the first time, you should know any special techniques or methods used. This can be best obtained by direct observation of the parents feeding the child. Because special children respond best to consistency and continuity, it is important to maintain the parents' current feeding program. Either a meal or a snack can be observed; but make sure that a utensil is used and the child is given a drink so you can see all aspects of feeding.

Structuring the environment before the meal can be easily accomplished. Some suggestions are:

- All food and equipment should be out of the child's reach.
- Ground cover can be used if the child is beginning to feed him/herself, to protect the floor.
- Family members can be strategically positioned at various spots around the table.
- For older handicapped children, you may want to have the meal set up family style (if the child can tolerate it).
- You may want to limit what is put on the table if:
  - the child has a decreased attention span
  - the child has a tendency to steal food from other people.
- If the child's vision and hearing are hypersensitive, remove all brightly colored objects and maintain a low volume of noise.

Preparing the Meal

Before the meal, the child should relax, whether by participating in a quiet activity or going through relaxation techniques.

(continued)

Relaxing the muscle tone before eating is important for several reasons:

- It makes the child more comfortable and also makes it easier to properly position the child.
- It increases the possibility of the child experiencing a more normal feeding process.
- It eases the feeding process for both child and adult.

Handling and Management

- Lay child on his/her back with a pillow under the child's head.
- Grasp child's hips with your fingers in front and your thumbs behind.
- Slowly rock forward until child is bearing weight on shoulders, upper back and neck.
    - The rocking and rotation help to relax the muscles
    - The rolling up helps to elongate the tight muscles
- Gently rotate child's hips from left to right.
- You can rest child's hips on your knees.
- Place your hands under child's neck and gently massage tight muscles.

Feeding Positions

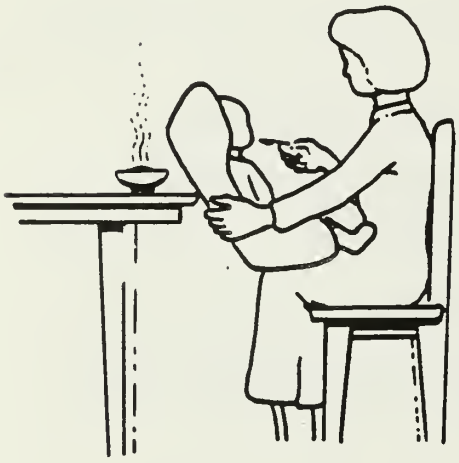
There are many feeding positions you can use. It is important that you be as comfortable as possible, as the child may sense your uneasiness, and become more irritable. General positioning suggestions for the child are:

- The child should have firm support in an upright position.
- The head should be in the midline position slightly flexed forward.
- The arms and feet should also be in the midline to avoid triggering developmental reflexes.

(continued)

- The chair should fit.
    - The feet should be firmly supported.
    - The table should be at the appropriate height.

For the child with minimal head and trunk control, maximal support is necessary. This type of child should be fed in a well-supported device such as a car seat, infant chair, or adapted high chair, not in your lap. The feeder should be in the front, at the child's midline.



- Use a table for extra support.
- Use a car seat or small infant chair (a wedge for your lap can be used if necessary).
- If using the wedge, the baby's legs should straddle your thighs, keeping them from scissoring (crossing due to increased muscle tone).
- The child's shoulders can be brought forward by applying light pressure to the chest, if the child should go into hyper-extension.
- If jaw control is necessary, you can use your forearm to keep the trunk in position so that your hands remain free.
- You can bring yourself closer to the table by bringing the child into a more upright position as head and trunk control increase.

For the child with increased head and trunk control, the upright position is recommended and either a sitting device or lap sitting can be used.

(continued)

Side sitting on lap

- To keep the child from going into extension, raise your leg under his/her knees a little higher than the leg that has his/her buttocks.
- Jaw control can be effected by bringing your arm around the child's back (rest your elbow on the table so you don't get tired).
- Place the food in front of the child (if possible) so the child can see where it is coming from.

As soon as head and trunk control develop:

- Use a chair or some type of sitting device. Do not prolong lap feeding.
- Avoid letting the child sit with a rounded back -- the child will compensate by lifting his/her chin, making swallowing much more difficult.
- If the child lifts his/her head, it increases the chance of going into total body extension.
- Make sure his hips and knees are as close to 90 degrees as possible.
- Legs should be slightly apart.

SPECIFIC TECHNIQUES TO ASSIST WITH FEEDING

There are many different techniques used before and during a meal to help a child with feeding problems. Different people have found various techniques more successful than others. The following examples have been used by the ILMPO Program* and found to be beneficial. However, it is important to note that individual parents may use other techniques for consistency of the individual feeding program.

*a program which has been incorporated into Community Resource Center, a part of Enable, Inc.

SPOONS

1. Never use plastic spoons.

2. Small stainless steel rubber-coated spoons are very good; they should not have a pointed end.

3. Spoon must fit without hitting teeth and should cover a large area on the tongue without stimulating the gag reflex.

FOOD TEXTURES/CONSISTENCY

1. You change the consistency of food by making it smooth, thick and/or dry.

2. Baby foods are too smooth; therefore, add potato buds, wheat germ, or powdered milk.

3. Junior foods have too many different consistencies.

4. Initially you want the food to be thick; otherwise it runs out and the child cannot do anything with it.

SPOON FEEDING

Important procedures when using spoons:

1. Place food just on tip of spoon.

2. Present spoon lower than head and in the midline.

3. Maintain the child in a good position.

4. When the mouth opens, allow just enough space to get the food into the mouth.

5. Spoon goes in straight and in midline; place it flat on the tongue.

6. Wait for spontaneous mouth closure; assist only if the child does not close the mouth.

7. When removing the spoon, bring it straight out of the mouth; do not remove the food from the spoon by scraping it against the upper teeth or gums.

8. Don't mix food textures on one spoon; during the meal you do mix textures, but not on the spoon.

9. Avoid spillage on the chin by using good jaw control. Dab the chin if it gets wet, but don't scrape the chin with the spoon because a lot of light touch stimulation around the mouth during feeding only increases muscle tightness and decreases coordination.

10. Try to get child on table foods as soon as possible.

CUP

The best cup is a small plastic cup with one side cut out in a half-moon shape. This type of cup can be tilted toward the child without requiring him/her to tip his/her head back and thereby reinforce the head extension. It is, however, important to use the child's own equipment if possible.

DRINKING

If the child is drinking from a cup with your assistance in holding the cup or giving some jaw stability, the following are basic considerations to remember:

1. Position the body so that it is symmetrical and the head is forward; use jaw control if the child needs it.

2. You should use jaw control for drinking even though you might not be using it for feeding because it is much more difficult to swallow liquids when drinking from a cup.

3. Present the cup to the child's midline.

4. Place it between the lips with the jaw closed.

5. Liquid is placed just to the edge and then you wait for the child to draw the liquid in.

6. The cup rests between the lips; it does not press down on the bottom lip or tongue.

7. If the child drools or drips the liquid out, then the flow of liquid might be too fast, position of the cup between the lips might not be correct, or lip closure may not be good enough.

SPECIFIC TECHNIQUES FOR COMMON ORAL PROBLEMS

Lip and Jaw Closure

Purpose

- Controls jaw extension and closure
- Keeps lips closed
- Prevents tongue protrusion
- Assists with normalizing chewing and swallowing
- Inhibits the bite reflex during cup drinking
- Teaches partial jaw opening and closing

From Behind

- Index finger under bottom lip
- Middle finger under chin just behind the tip of the chin (stop tongue protrusion)
- Arm behind head to maintain good head position
- Optional: thumb on cheek for added control

From Front

- Thumb under bottom lip
- Middle finger stretched under chin behind the tip of the chin
- Index finger on cheek

Prior to the meal give deep pressure strokes to the facial area. This facilitates the relaxation of facial muscles and prepares the child for the eating process. Afterwards, give deep pressure to the lips while they are held closed.

Tongue Thrusting

1. Spoon feeding inhibits tongue thrust; chewing helps to stimulate more mature tongue movements and to inhibit the tongue thrust.

2. Place the spoon in the middle of the tongue and press down when removing the food from the spoon.

3. If tongue thrusting continues to be a problem, take the bowl of the spoon and lightly stimulate under the tongue, on each side of the frenulum.

4. Non-sticky foods are recommended. Try to avoid foods with the consistency of peanut butter.

5. <u>The bowl of the spoon should never make direct contact with the hard palate!</u>

Bite Reflex

As described before, the bite reflex is stimulated by making contact with the teeth or gums. Obviously, the best way to avoid stimulating this reflex is to avoid contact with those areas.

1. For the child with a severe bite reflex, deep pressure stimulation around the face, prior to the meal, is often helpful. (a)

2. Give deep pressure to the lips with your finger or the bowl of the spoon. (b)

3. Empty the spoon on the middle of the tongue, giving downward pressure.

4. If the reflex is stimulated, do not jerk the spoon out of the mouth. Gently rock it from side to side, while pulling steadily outward. (c) If this doesn't work, give deep pressure strokes to the outside of the face as in (a).

Gag Reflex

It is very important for you to be aware if the child has a strong or weak gag reflex.

1. For the hyper-responsive child, place the food on the very front of the tongue with the first spoonful. Gradually place it further and further back on the tongue, stopping at 1/3 of the way back, or where the child is most comfortable and not gagging.
2. For the hypo-responsive child, place the food 1/3 way back on the tongue. The most important issue is to maintain a good head position (neck slightly flexed forward and in midline). If the child maintains a good position, the possibility of choking is decreased significantly. Also, do not overload the child's spoon. Give only small amounts at a time.

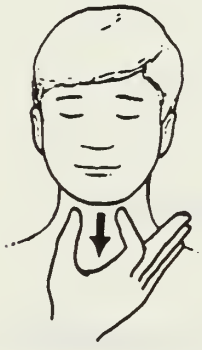
Sucking

Many times the child will need assistance to start sucking. This especially needs to be done with bottle drinking.

1. Give deep pressure strokes to the outside of the face and mouth.
2. When giving the bottle, push and pull the bottle inward and outward. At the same time, give deep pressure strokes to the cheeks.

Swallowing

Swallowing incorporates the muscles of the mouth and chin. Sometimes children have difficulty coordinating these two areas. If the child appears to be having difficulty, there is a simple procedure that can be used to stimulate swallowing.



1. Positioning is very important. Head in midline, slightly flexed forward.
2. After the food has been placed in the child's mouth, give deep pressure upward on the soft pad behind the chin bone.
3. Afterwards, give 1 or 2 deep pressure strokes down the neck with forefinger and thumb on either side of the esophagus.
4. Repeat entire procedure only when needed. Try not to overstimulate.

Oral Hygiene

There is a lot of emphasis today placed on the importance of good oral hygiene. This holds true for special needs children also--especially for those children who are or have been on various medications for a long time.

All feeding programs should be followed by a vigorous oral hygiene program which should include tooth brushing with a toothbrush and tooth paste. Toothletts or a soft cloth can be used in place of the toothbrush. Proper positioning and midline orientation are as important for toothbrushing as they are for feeding. Parents should be encouraged to have their children get routine dental check-ups.

IMPORTANT INFORMATION YOU SHOULD KNOW BEFORE FEEDING A CHILD

1. The types and textures of foods the child is eating.
2. Food preferences
3. Usual amounts per meal
4. Feeding schedule
5. Amount of time it takes to feed the child per meal
6. Special positioning (equipment vs. lap feeding)
7. Utensils used to feed the child (spoons and cup or bottle)
8. Problems with chewing, gagging, or choking?
9. Special stimulatory techniques to help the child eat

EATING AS A SOCIAL EXPERIENCE

- Learning good eating habits is important for healthy development
- Offers an opportunity for parents and child to interact
- Encourages child to develop trust in self and others, by allowing child to set rhythm of feeding
- Do not encourage overfeeding or forced feeding, especially at the end of the first year when all children's appetites slow down as the rate of growth decreases. Overfeeding during this time can affect the child's eating habits over a lifetime, and could lead to overweight problems later in life.

The overall goal in the feeding situation is to increase the consistency of the diet as the ability to manipulate food improves. Monitoring the child's intake of food is important. Any questions about what or how the child is eating should be directed to your child's physician or nurse practitioner.

Functions of Food

- Growth
- Maintenance
- Catch-up

Food also functions to teach the child how to use his/her body (eyes, hands, mouth, throat) and allows child to get to know foods.

(Table 2 in Appendix refers to nutrients, functions, and sources.)

CARBOHYDRATES	Starches and sugars which provide the body's main source of energy. Found mostly in plant foods and milk.
PROTEINS	Primarily used for growth and repair, protein is found in meat, dairy products, eggs, poultry, legumes, fish, etc.
FATS	Concentrated sources of energy which carry vitamins and minerals. Found mostly in animal products such as butter, cream and meats, and in margarines, oils and nuts.
VITAMINS AND MINERALS	Substances used in the body for maintenance, repair and many other bodily processes, they are essential in small quantities. Found mostly in fruits and vegetables and in meats, milk and grains.
WATER	Essential for all bodily processes, water is needed by everyone in large amounts daily.

Your child needs all of these foods every day, except when on a special diet which eliminates a certain food or food group. As a rule of thumb, your child needs 1 Tablespoon (T.) of each food at each meal per year of age. For example, a good meal for a 3-year-old child would be:

(continued)

3 T. Meat	3 T. Fruit
3 T. Potato	4 Oz. Milk
3 T. Vegetable	1/4 - 1/2 Slice of Bread

For more detailed information, see Table 3. Remember that these are general figures for normal children and may have to be adjusted for your special child.

Progression of Foods

All infants begin life with breastmilk or some type of formula. The progression to other types of food depends on the baby's readiness, which is dependent on a number of factors. The introduction of semi-solid or pureed foods usually begins by the age of 6 months. However, the introduction of foods to children with special needs may vary considerably, and is determined by the child's developmental readiness. While handicapped children may be slower in accepting new and/or solid foods, it is extremely important that they be encouraged to do this.

Some children may have to be fed and/or may be unable to take solid foods for their entire lives, but it is important for their sense of independence as well as their nutritional status that they be allowed and encouraged to do the most that they can do.

Specific signals that the child may offer the caregiver to show that he or she is ready to try new foods may be as direct as reaching for someone else's plate or putting non-food items in his or her mouth. Other signals that the child may offer include the ability to hold the head up, lateral movement of the tongue and accepting fluid from a cup. While these actions might not be as easy for a handicapped child to perform, they can be controlled and taught by the caregiver. The child's stage of development and awareness of the eating process will determine the type and texture of the food offered (see Table 4). As always, attention must be paid to he special diet that child requires.

The feeder should take care to make the feeding time a pleasant one and as free of other distractions as possible. Positioning is important, as has been explained by the occupational therapist. For the caregiver's sake, it is important that expectations are not too high for the child to reach at any given time. Each situation is unique.

Being aware of the feeding patterns of healthy children who have normal developmental milestones will result in a greater understanding of the feeding patterns of children with special needs. (See Table 4, for Progression of Food Textures, and Table 5, Introduction to Table Foods.)

Disabled children, for both nutritional and developmental reasons, may be at greater risk to become overweight or underweight. Growth charts are helpful in monitoring your child's weight; if your child begins to lose or gain weight or the child's growth curve begins to level out, you will be on top of the situation before it becomes serious. Growth charts are available through your doctor's office. The chart's purpose is to indicate your child's actual height and weight in comparison to his former growth, and in comparison to other children his or her age. For some conditions such as Down syndrome, there are special growth charts available. Unfortunately, a true measurement of height is often almost impossible to measure when a severely disabled child's spine is involved, and comparison to healthy children on a growth chart is not always helpful.

When a child's growth is impaired, it is often difficult to assess whether the weight loss is due to poor food intake or some medical condition. You may be asked by your family physician or nurse to monitor your child's food and beverage intake over a period of time, so that this information can be used to assess the cause of the weight loss.

Overweight

Children with Down syndrome, myelomeningocele, spastic Cerebral Palsy, and Prader-Willi syndrome are likely to have weight problems. Being overweight can add to the handicap by decreasing mobility, and the child may be at greater risk of complications when undergoing surgery. Fat deposits can cause skin ulcers and infections. In addition, obesity can be an emotional and social handicap.

Because there is no simple or effective treatment for obesity, prevention is the key element in the management of these children. The child who is cannot walk needs only 75% of the calories needed by a child who can. Low-fat and low-calorie foods are appropriate choices for these children. Because diets restricted in calories are not as easy to balance, special care must be taken to assure that all of the child's nutritional needs are being met. Compare the daily menu with the Basic 4 Food Groups to assess adequacy.

Underweight

Although conditions such as athetoid Cerebral Palsy, minimal brain dysfunction, autism, and congenital anomalies can cause a child to be underweight, it is not always the result of a medical condition. Short feeding periods and loss of food from the child's mouth during feeding can all contribute to the problem. This child is also at nutritional risk, because, as noted above, low-calorie diets are more difficult to balance. Vitamin and mineral deficiences are common in underweight children. Care must be taken to provide nutrient-dense food which is attractive and palatable, so that the child will be inclined to eat it. See Table 6 for suggestions, which may also be useful in feeding the "picky eater." (See Appendix for suggestions for High Calorie Foods, Table 6 and Supplements, Table 7.)

Constipation

Constipation often results from low muscle tone, lack of activity and poor diet. To help prevent constipation:

1. Increase fluids - Child should be drinking 4 - 6 glasses of liquid per day, especially as water or juice. The liquid in soups and sherbets also helps to prevent constipation. Prune juice is a particularly good treatment if constipation does occur.

2. Increase fiber - Include plenty of whole grains, fruits and vegetables in the diet. Fiber in the diet also encourages chewing and strengthens the muscles in the mouth. See Table 8, "Here's How to Add Extra Fluids and Fiber."

3. Increase activity - Almost any type of activity will help. If the child can't move, massage the stomach area and gently and rhythmically bend the legs up into the body.

Diarrhea

Diarrhea can be defined as frequent, watery stools. It is caused by irritation of the intestines, emotional disorders and increased mucus secretions. Dehydration is the most serious complication associated with diarrhea. Younger children are at greater risk of dehydration because their bodies require more fluid per pound of body weight than older children or adults. Most cases of diarrhea are mild and can be treated at home, but your family physician should be consulted if diarrhea persists.

(continued)

When a child has frequent loose bowel movements, clear liquids are usually recommended to replace water and electrolytes. Sometimes the physician may recommend Pedialyte (sterilized glucose water with electrolytes) to start off. For infants with diarrhea, small amounts of diluted formula or breastmilk may be given. No formula or cow's milk should be offered. Infants should be given an average of two ounces of fluid every hour or about a cup over the span of six hours. It is better to give small amounts of liquids frequently than large amounts of liquids occasionally.

The severity and frequency of the diarrhea and age of the child should dictate the diet. Please consult your physician for the most appropriate diet for your child.

The diet for children who have diarrheal stools every four to six hours should include plenty of clear fluids and soft, bland foods such as mashed banana, rice cereal, applesauce and dry toast. Parents should limit the amount of fruit and fruit juice, fatty, rich and spicy foods, all of which can be irritating to the intestines.

Dental Health

Healthy teeth are important for all children, but especially for children who have feeding conditions that affect what and how much that child is able to eat.

Good dental health begins at the child's birth. "Bottle syndrome" occurs when the child is put to bed with a bottle and falls asleep with fluids in his or her mouth. This is especially a problem when liquids have a high content of sugar (such as Kool-Aid and sweetened juice). For further information on foods which should be avoided in an infant's diet and tips on how to promote good oral hygiene, refer to Table 9 in the Appendix.

Food and Drug Interactions

There are certain conditions common to the developmentally delayed population which are likely to require the long-term use of drugs, some of which can interact badly with the child's diet and/or cause side effects which negatively affect nutritional status. There are some simple and direct guidelines for avoiding or reducing this problem. (Refer to Table 10 in Appendix.)

Iron Deficiency Anemia

Iron deficiency anemia is common in many young children. It is caused by an inadequate supply of iron in the diet. Lethargy or excessive tiredness is an early warning sign of iron deficiency anemia, which can be diagnosed by a simple blood test. The problem occurs in many children who drink large amounts of milk, usually from a bottle, which leaves them food full to eat foods high in iron such as iron-fortified cereal, red meats, dried beans, fortified grain products and dark green leafy vegetables. Foods rich in vitamin C and sources of protein help the body use the iron.

IT IS IMPORTANT TO REMEMBER THAT EACH CHILD IS AN INDIVIDUAL, AND HIS/HER DIET SHOULD BE CUSTOMIZED AS MUCH AS POSSIBLE TO MEET THAT CHILD'S NEEDS.

Workshop 2--FEEDING

RECOMMENDED READING

1. Connor, F.P., G.D. Williamson, and J.M. Siepp, Program Guide for Infants and Toddlers with Neuromotor and Other Developmental Disabilities. Teachers College Press, New York, 1978.

2. Finnie, Nancy R., Handling the Young Cerebral Palsy Child at Home. E.P. Dutton and Company, Inc., New York, 1975.

3. Smith, Mary Ann Harvey; McFadden, Susan and Nuckolls, Leah Jan, Feeding Management of a Child with a Handicap. University of Tennessee Center for the Health Sciences, Child Development Center.

BIBLIOGRAPHY

1. Connor, F.P., G.D. Williamson, and J.M. Siepp, Program Guide for Infants and Toddlers with Neuromotor and Other Developmental Disabilities. Teachers College Press, New York, 1978.

2. Finnie, Nancy R., Handling The Young Cerebral Palsy Child at Home. E.P. Dutton and Company, Inc., New York, 1978.

3. Gallender, Demos, Eating Handicaps. Charles C. Thomas, Publisher, Springfield, Illinois, 1979.

4. Farber, Shereen, Sensori-Motor Evaluation and Treatment Procedures for Allied Health Personnel. Indiana University Foundation, 1974.

Workshop 2--NUTRITION

BIBLIOGRAPHY

Books for Parents

1. Caring and Cooking for the Allergic Child. L.L. Thomas, Sterling Publishing Co., New York, 1980.

2. Child of Mine: Feeding with Love and Good Sense. Galen's, 35 South Street, Needham, MA 02192.

3. Coping with the Gluten-Free Diet. M.N. Wood, Charles C. Thomas, Springfield, IL, 1982.

4. Family Health Cookbook. A. White and the Society for Nutrition Education, David McKay Co., Inc., New York, NY.

5. Feed Me! I'm Yours. V. Lansky, Bantam Books, New York, NY, 1979.

6. Mealtimes for People with Handicaps: A Guide for Parents, paraprofessionals and Allied Health Professionals. N. I. Pensis and M. A. Maloney, Charles C. Thomas, Springfield, IL, 1983.

7. Nutrition for Your Child's Most Important 3 Years: Birth to Age Three. S. Castle, Simon and Schuster, Inc., New York, NY, 1984.

8. Recipes for Smooth Food. G. Rosenthal, Galen's, 35 South Street, Needham, MA 02192.

Cookbooks for Use With Children

1. Cook and Learn. Veitch and Harms, Addison-Wesley Publishing Co., Reading, MA. Pictorial classroom recipes where each child makes own portion, plus teacher's guide.

2. Kids are Natural Cooks. Ault and Uraneck, Houghton Mifflin Co., Boston, MA.

3. Love At First Bite. Jane Cooper, Random House, Inc., New York, NY.

4. Mother Child Cookbook. Nancy J. Ferreira, Pacific Coast Publishers, Menlo Park, CA.

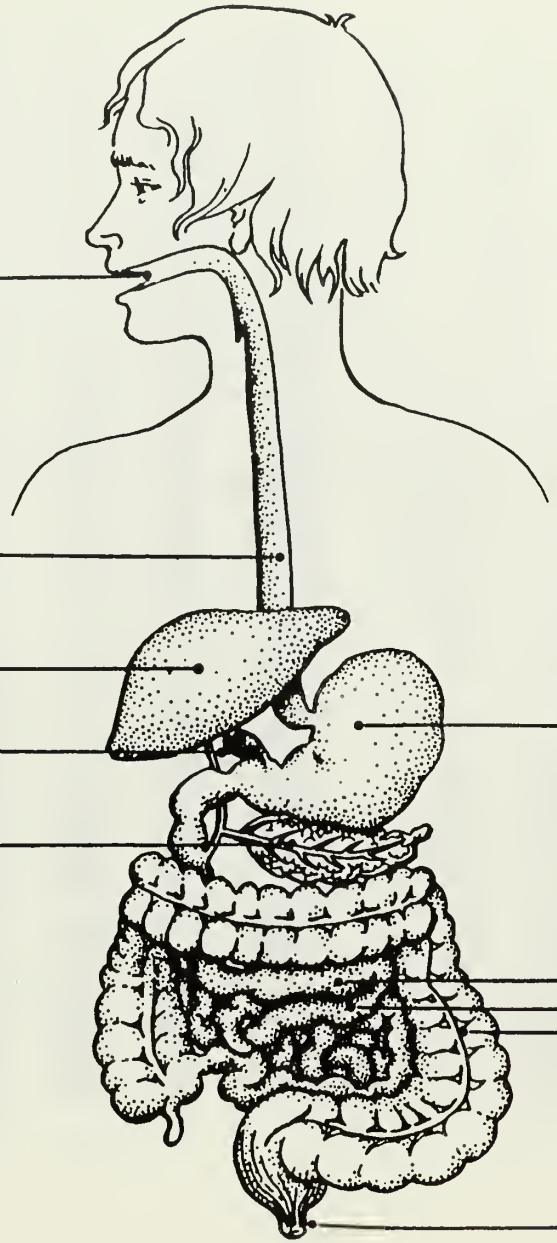
5. The Taming of the Candy Monster. Vicky Lansky, Meadow Brook Press, Deephaven, MN. How to set up a cooking program, with a motor coordination emphasis.

How the Body Breaks Down Food into Nutrients and Wastes

Mouth — entrance to the digestive tract. Your teeth shred and tear big chunks of food into smaller pieces. Enzymes in saliva begin to dissolve some carbohydrates. Enzymes are substances made by the body. They ignite chemical reactions that transform one substance into another. Without enzymes, digestion would take days instead of hours, and the nutrients and energy in the food would be released too slowly.

Esophagus — a muscular tube that squeezes food to the stomach in 7 seconds.

Liver, Pancreas, and **Gallbladder** — produce enzymes and other chemicals to help break food down.



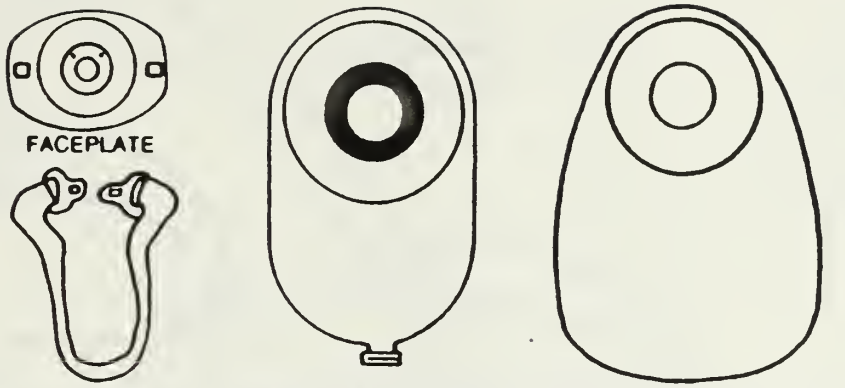
Stomach — contains acid that dissolves food into a liquid. Food is churned and mixed for 3-4 hours. The stomach holds about 1½ quarts.

Small Intestine — continues to break down food. When food is completely broken down into carbohydrates, fat, protein, vitamins, minerals, and water, it travels through the wall of the small intestine and into the bloodstream. Food stays in the small intestine for about 8 hours.

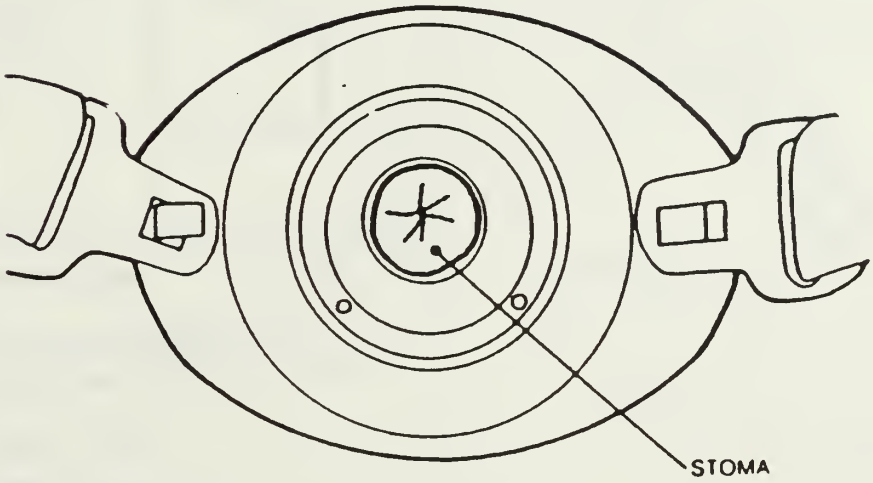
Villi — millions of small, fingerlike projections that cover the inner surface of the small intestine and increase its surface area. Villi enable the small intestine to absorb nutrients faster (see figure 1-1).

Large Intestine — collects the parts of plants the body doesn't digest such as celery strings and seeds. Also collects old blood cells and other waste from the body. Water is drawn in through the walls to make excretion of waste easier.

Anus — waste exits.



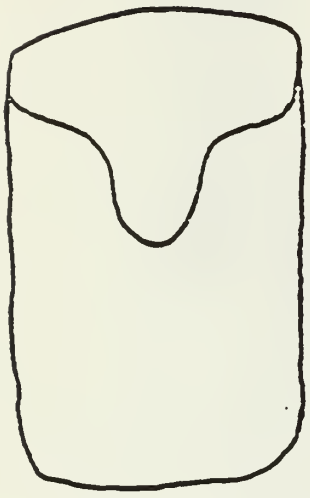
Collection Appliances



Faceplate of a Collection Appliance
(Placed Over the Stoma)

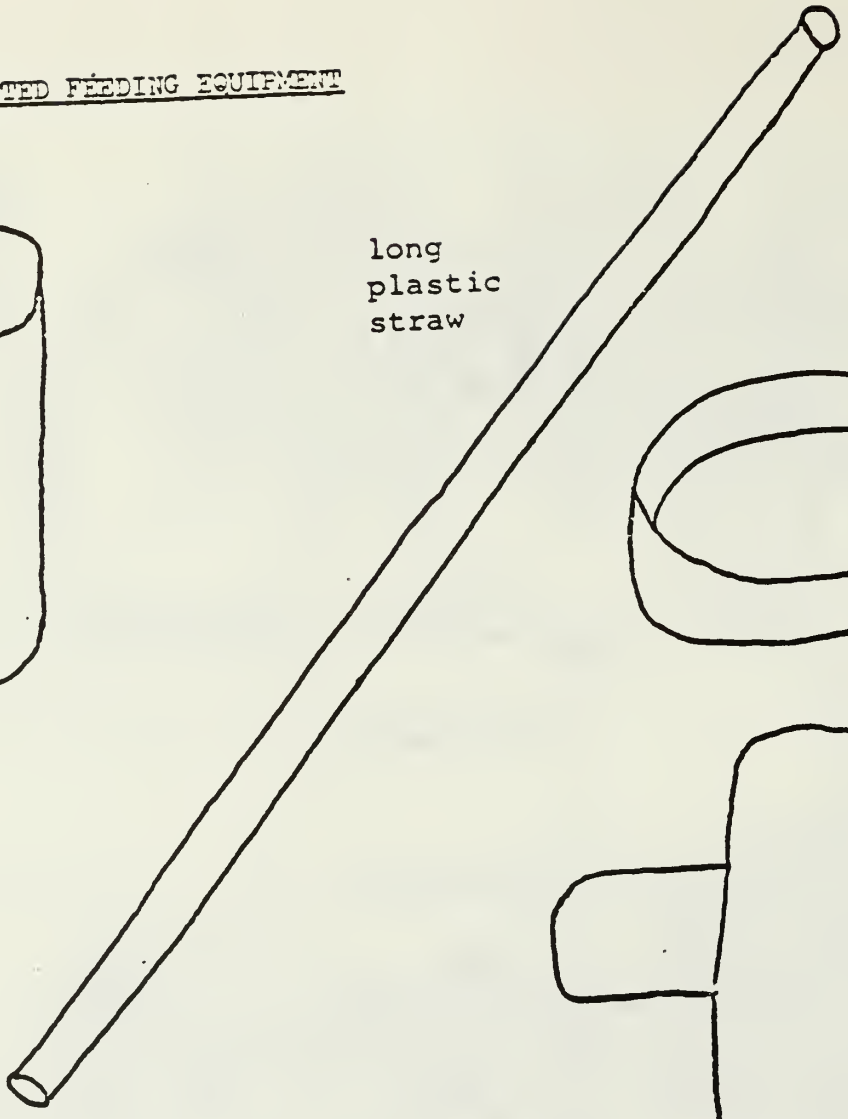
Source: Medical Aspects of Developmental Disabilities in Children Birth to Three. James A. Blackman, M.D., University of Iowa, 1983.

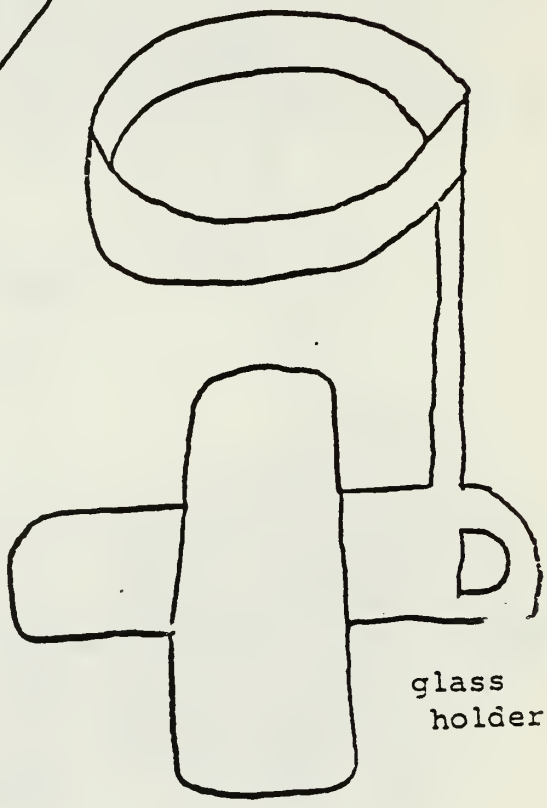
ADAPTED FEEDING EQUIPMENT



nosey cup

long
plastic
straw



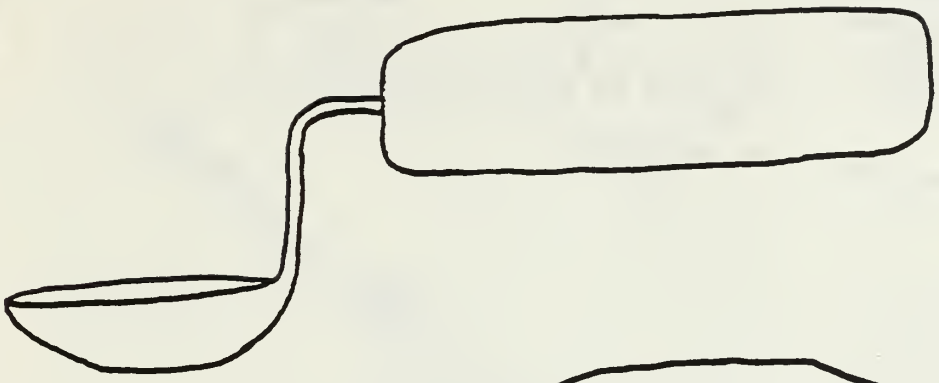


glass
holder

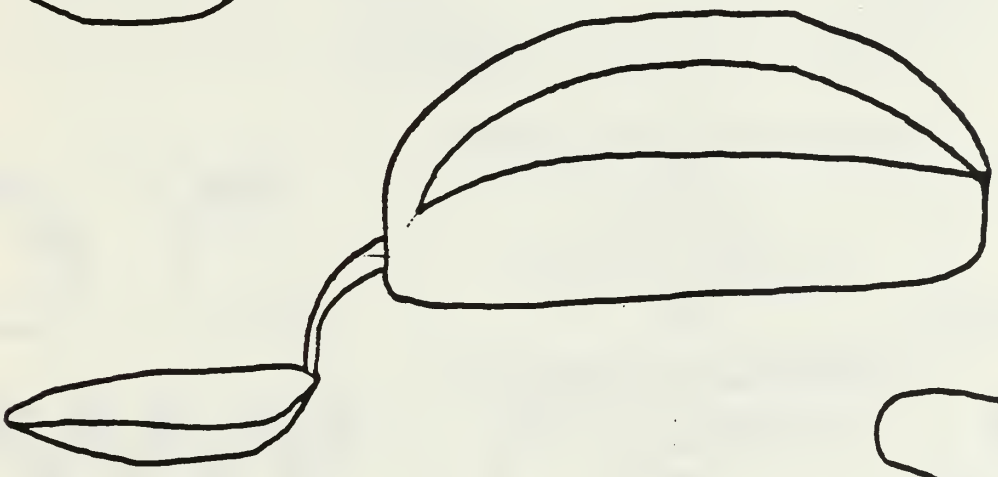
pedestal
cup

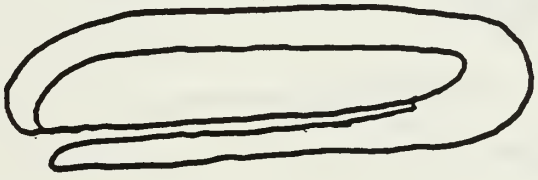
2 handled cup

ADAPTED FEEDING EQUIPMENT

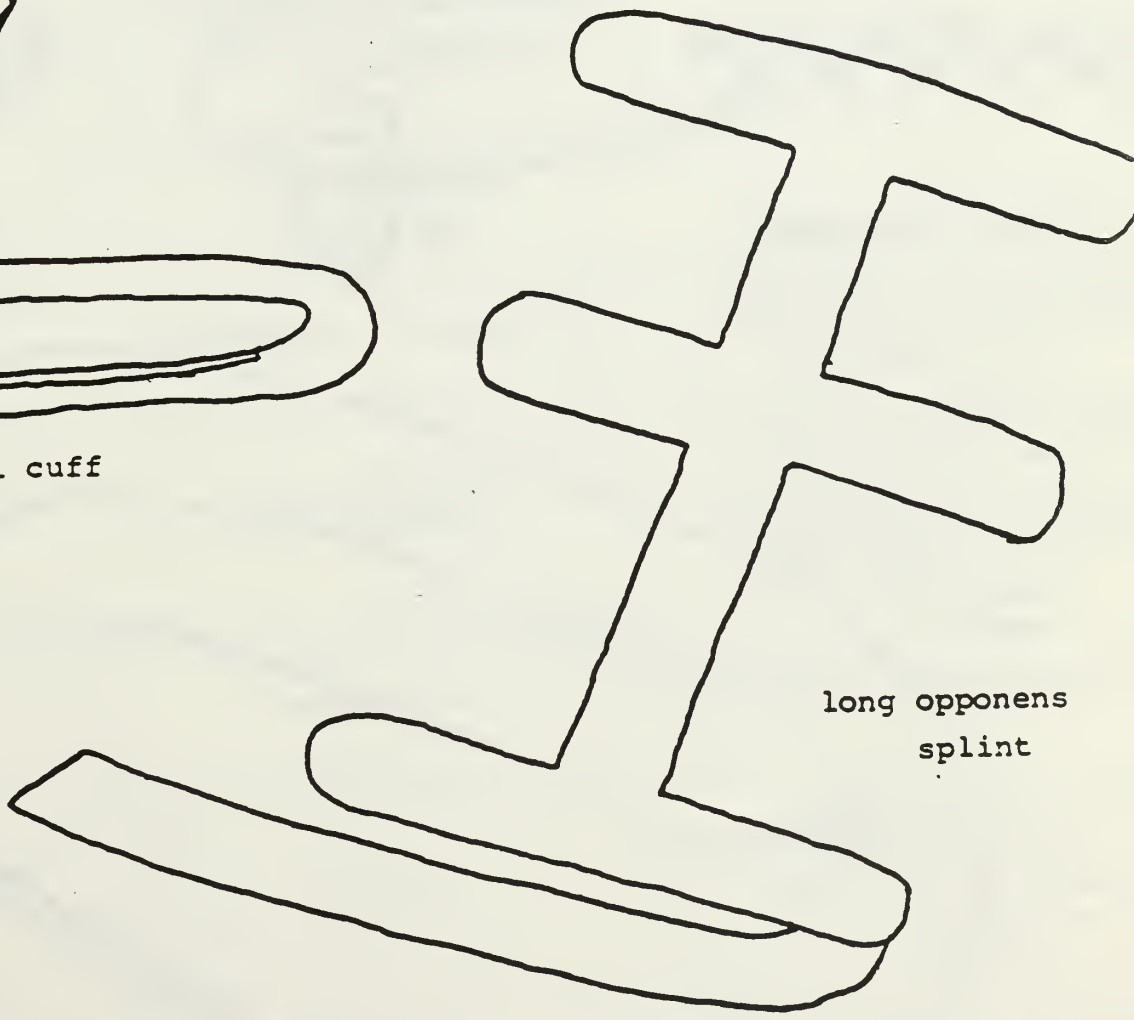


built-up handle spoons





universal cuff



long opponens splint

INDEPENDENT FEEDING EQUIPMENT

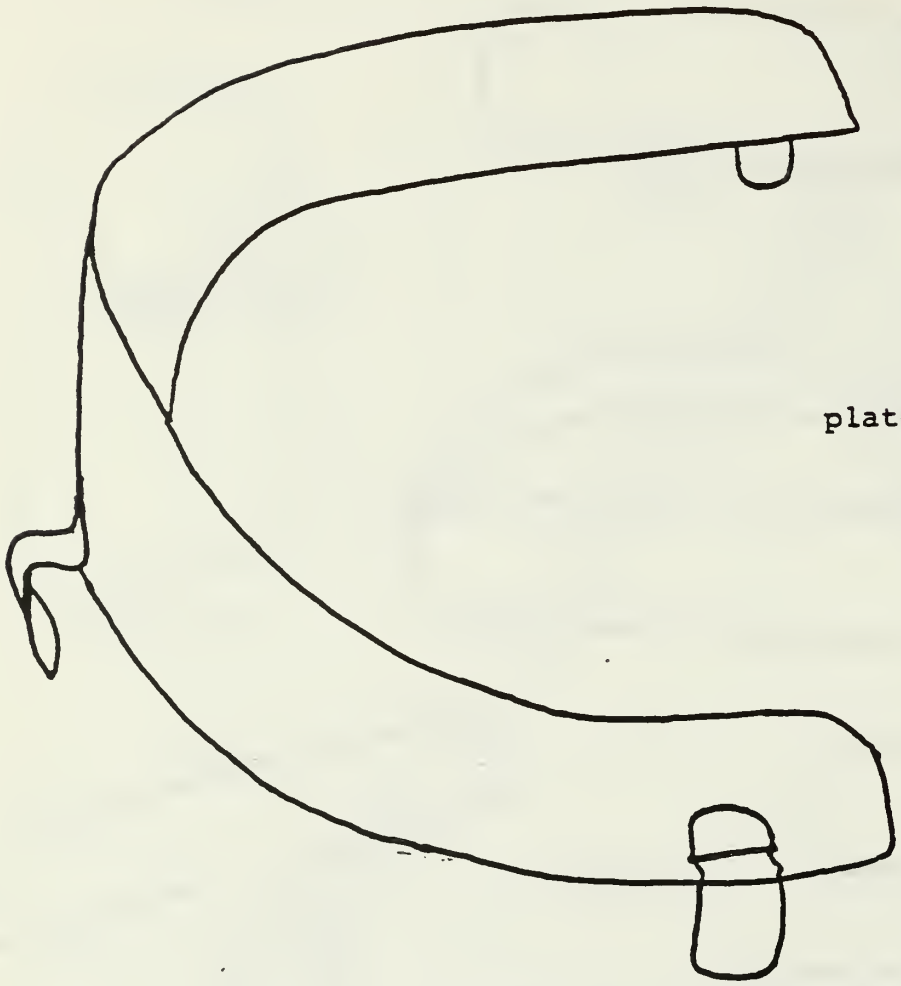
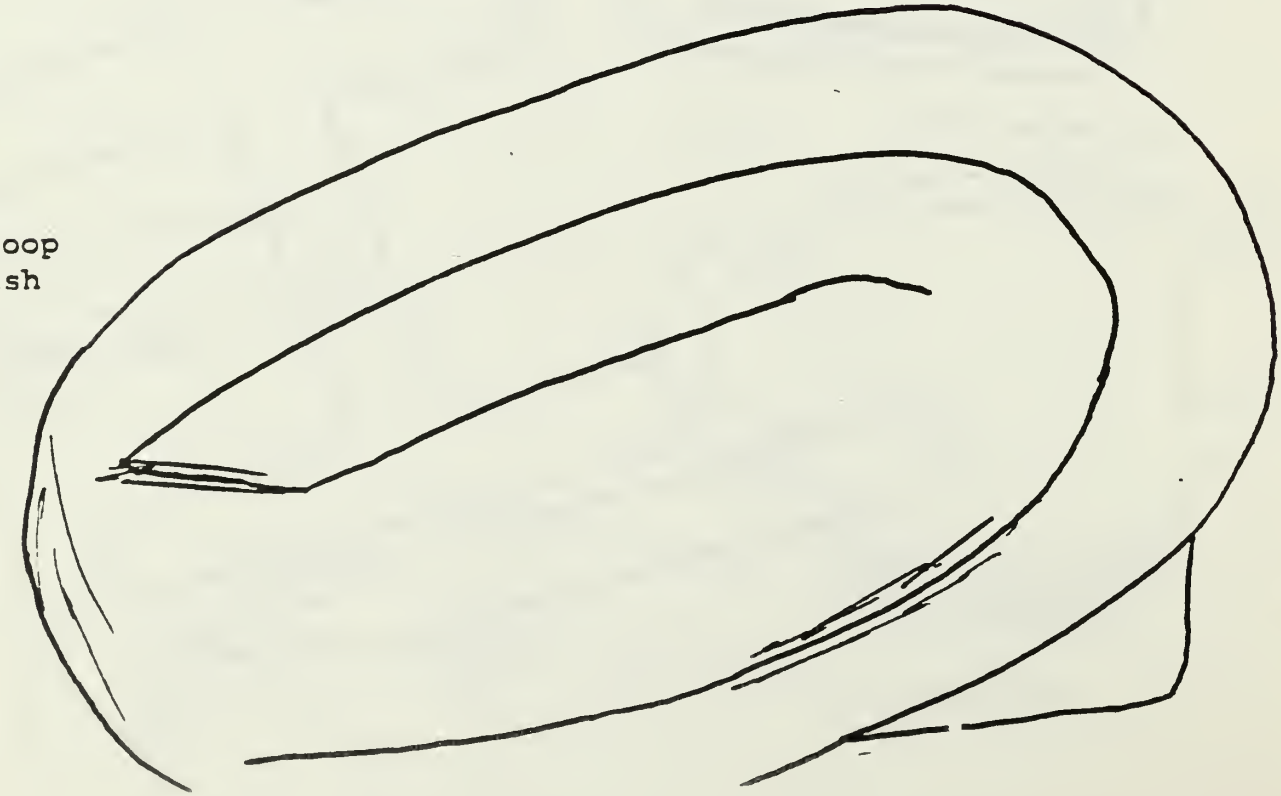


plate guard



scoop
dish

TABLE 4

Feeding Time

PROGRESSION OF FOOD TEXTURES FOR HANDICAPPED CHILDREN

When your child	He / She is ready for	Suggested Foods
handles food through a sucking action and cannot move food to sides of mouth	thickened puree or soft mashed foods.	Mashed potatoes, well cooked mashed vegetables, soft diced fruits, cooked cereal, applesauce, yogurt.
begins to show up and down chewing and is able to move food to sides of mouth	ground foods progressing to chopped table food.	Ground fruits and vegetables, ground non-stringy meat mixed with gravy. Chopped meats and casseroles, cut-up cooked vegetables and fruits, grilled cheese sandwich, french-fried potatoes.
has mature chewing moves food freely from side to side of mouth	regular table foods.	Small pieces of chopped meats, crispy tendered vegetables & fruits.
begins to bring food to mouth and has adequate oral motor skills	finger foods.	Oven dried toast, peeled hot dog, banana slices, dry cereal, cheese sticks, large curd cottage cheese, soft cut-up fruit, graham crackers, fish sticks.
begins to spoon feed self and has adequate oral motor skills	food that sticks to the spoon.	Yogurt, applesauce, mashed potatoes, cooked cereal, cheese, cottage cheese, puddings, macaroni and cheese.

Introduction To TABLE FOODS

"I want something to eat besides my bottle!"

1. When your child is ready for table foods, serve SOFT, MASHED Table Foods.

SUGGESTED	TO AVOID
Mashed potatoes	Raw vegetables
Well cooked mashed vegetables (carrots, stringless green beans)	Large pieces of meat or any type food
Soft diced fruits (bananas, peaches, pears)	
Slices of peeled vienna sausage	
Liverwurst	
Well cooked ground meats	
Yogurt	
Tuna fish	

Finger Foods

"Look Mom, I can eat with my hands."

2. Foods should be soluble in the mouth to prevent choking.

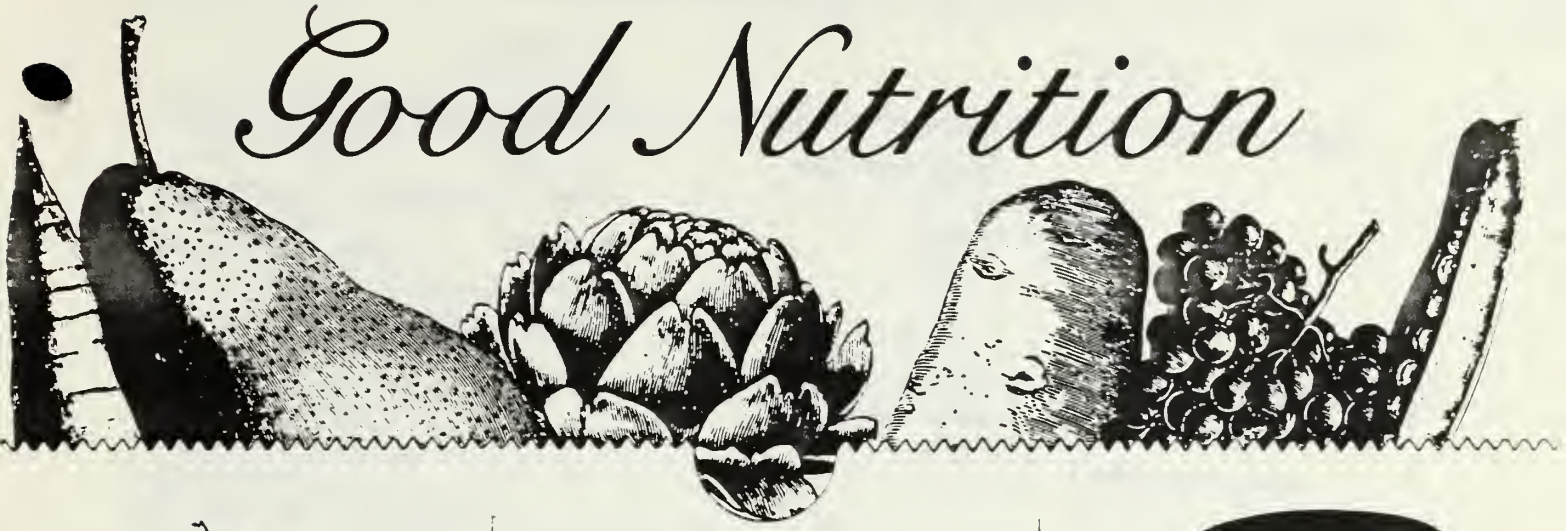
SUGGESTED	TO AVOID
Oven dried toast	All dried fruits-raisins, apricots coconut, dates
Peeled hot dogs	American processed cheeses
Banana slices	Peanut butter
Peeled seedless grapes	
Soft cut up fruit or canned fruit	
Mealy apple slices (remove skin)	
Cheerios	
Graham crackers	
Canned or steamed vegetables (broccoli, green beans)	
Cheese sticks, hard cheeses (Cheddar, Monteray Jack)	
Large curd cottage cheese	
Small pieces of nonfibrous meat (meat should be moist or use a sauce such as tomato or meat sauce) Try ham, meatballs, pork, chicken, organ meats.	
Scrambled eggs	
Fish sticks	

3 Introduction of more TEXTURED foods from Family Meals.

"Mom still feeds me sometimes, but I eat the same foods as everyone else"

SUGGESTED	TO AVOID
Thick stews	Casseroles with crunchy foods like nuts, water chessnuts, celery
Casseroles-mixed meat sauce and pasta -vegetable and cheese	Chunks and pieces of food that splinter, such as potato chips
Vegetable soups	Tacos
Shoestring potatoes	Lettuce
French fried potatoes	
Quiches, souffles	
Grilled cheese sandwiches	
Lasagna-meat or meatless	

Good Nutrition



FOOD

is made up of nutrients.

NUTRIENTS

supply the body with energy.
Provide the raw materials
the body needs for growth.

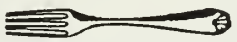
The amount of food your child needs depends on gender, age, general health, activity level and size.

The developmentally delayed child requires the same nutrients as any other child.

Your Child's

physical, mental and emotional health is dependent on good nutrition. A good diet provides the nutrients needed for growth.

A child's *appetite* may vary from meal to meal. General health, oral-motor function, activity and age in.. .ice how much is ..ten.

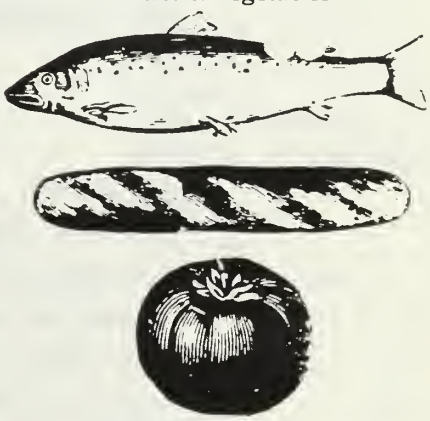


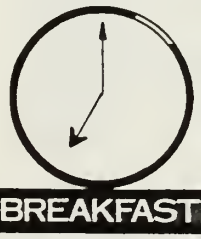
MEALS for your child need not be planned separately from family meals. Simply adjust the texture and portion size according to his/her needs. Here are sample meal plans to suit children and adults.

Adjust them to the food and mealtime preferences of your family.

4 FOOD GROUPS

Milk
Protein
Bread & Cereal
Fruits & Vegetables





BREAKFAST

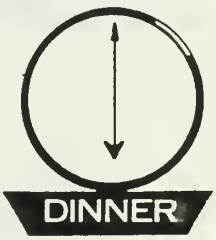
Fruit, Fruit Juice
Cereal, Egg or both
or Bacon, Cheese, Hot Dog
Peanut Butter Toast
Toast Bread, Muffin, Bagel
Milk to drink and with Cereal

LUNCH

Cheese, Egg, Meat or Peanut Butter
Bread
Bits of Vegetables & Fruit
Milk, Tea or Soup made with Milk
Snack-cereal & Raisins

SNACKS

Ice cream, Yogurt with Granola



DINNER

Meat, Chicken, Fish, Cheese
Egg or Main Dish made with
Dried Beans or Peas
Dark Green, Leafy or
Orange Vegetable or Fruit
Bread, Biscuits, Rolls
Rice or Noodles

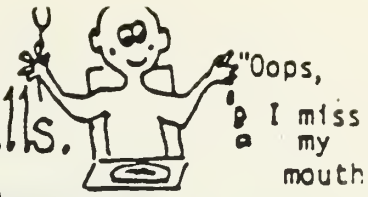
TABLE 3

FOOD GROUP SERVING SIZE FOR CHILDREN

(Adequate nutrients bu not calories)

Food Group	Number of servings per day	Serving sizes for age Pre-school	School	Teen
Milk (yogurt, cot-cheese, cheese, ice crm)	3 4	6 oz	8 oz	 8 oz
Meat (egg, fish, poultry, beef, pork, lamb) (also nuts, peanutbutter, dry peas,beans)	2	1 oz	2 oz	3 oz
Vegetables				
Orange, tomato (vitamin C)	1	1/2 c	1/2 c	1/2c
Carrots, sweet potatoes, broccoli, spinach)	2x/wk	1/4 c	1/2 c	1/2c
Other fruits and veggies	2-3	1/4 c	1/2 c	1/2c
Grain	4			
Bread		1/2sl	1 sl	1 sl
Cereal, dry		1/3 c	1/2 c	1/2c
cooked		1/4-1/2 c	1/2 c	1/2c
Maccaroni, rice, potato		1/4 c	1/2 c	1/2c

Anderson, Dana Derrick, Special Feeding Clinic. Univ. of Mass. Medical Center, Worcester Ma.



4. Feeding the FLOOR: Beginning of self-feeding skills.

SUGGESTED	TO AVOID
Foods that will adhere to a spoon when scooped.	Foods that slide off a spoon.
Yogurt	custards, jello
Applesauce	canned fruits
Mashed potatoes	soup
Cooked cereal - oatmeal, cream of rice farina, grits	
Cheerios soaked in milk	
Puddings	
Macaroni and cheese	
Cottage cheese	
Egg salad	
Mashed pork and beans	

*To develop self drinking skills use plastic tumbler with a small amount of liquid.

5. CHEWING FOODS: Introducing more fibrous foods.

Small pieces of chopped fibrous meats-steak, roast and crispy tendered vegetables and fruits

INTRODUCTION OF FRUITS AND VEGETABLES IN A GRADUATED PATTERN

It is best to introduce one texture at a time. Delay adding textured foods that are juicy such as peaches and pears until stage 2.

VEGETABLES

-1-	-2-	-3-
Tomatoes	COOKED eggplant	COOKED lentils	RAW carrots
Zucchini	peas	cabbage	celery
Mushrooms	potato	carrots	broccoli
Bean Sprouts	squash	cauliflower	brussel sprouts
Pickles	broccoli	corn	cabbage, coleslaw
Pared cuke slices	beets	asparagus	cauliflower
		fresh greens small pieces	artichokes
			radishes
			turnips, water chessnuts

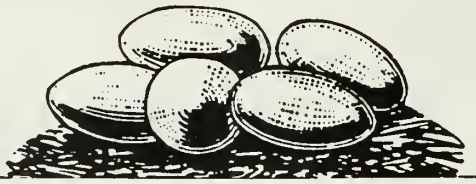
FRUITS

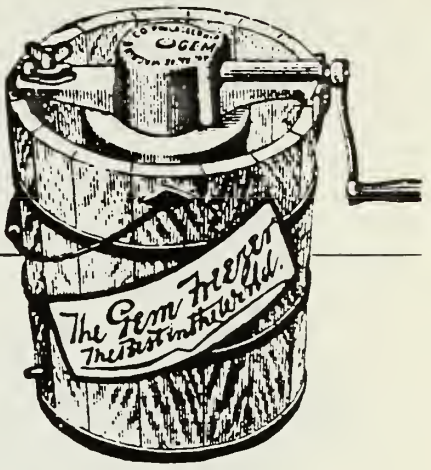
-1-	-2-	-3-
Canned fruits water or juice packed	blackberries	dried fruits
Cantaloupe, muskmelon	fresh figs	raw pineapple
Apricots	plums	shredded coconut
Strawberries	watermelon	
Seedless grapes	peaches, pears	
Oranges		
Bananas		

Prepared by Denise Wolf, Nancy Couhig, R.D., M.S., Peggy Pipes, R.D., M.P.H.
Nutrition Section, Clinical Training Unit
Child Development and Mental Retardation Center
University of Washington
November 1978

Calorie Boosters

for Weight Gain





IF YOUR CHILD

is having trouble gaining weight, here are some ways to hide extra calories.

Powdered Skim Milk

Add 2-4 tablespoons to 1 cup milk. Mix into puddings, potatoes, soups, ground meats, vegetables or cooked cereal.

Carnation Instant Breakfast (a food supplement)

Add to milk or puree fruit to make milkshakes.

Eggs

Blend into milkshakes or other beverages. Add to casseroles, hamburger or soups.

Corn Oil, Margarine

Add to puddings, casseroles, sandwiches, vegetables, soups, cooked cereal.

Cheeses

Give as snacks or in a sandwich. Add to casseroles and potatoes.

Dried Fruits

Serve as snacks or mixed into cereals or desserts.

Peanut Butter

Serve on toast, fruit or as peanut butter logs (see recipe).

Ice Cream

Use in milkshakes.

Wheat Germ

Add a tablespoon or two to cereal. Mix into cookie batter, casseroles, puddings, etc.

SUPER SHAKE

1 cup ice cream
1 cup milk
1 package Carnation Instant Breakfast

Blend well.

PEANUT BUTTER LOGS

1 cup milk (nonfat dry crystals)
½ lb. peanut butter
½ cup honey
1 cup rice krispies
1 cup 100% bran flakes
½ cup raisins

Combine all ingredients well. Flatten mixture in a large pan. Chill overnight. Cut into 2" x 1" servings.

SUPER PUDDING

2 cups milk
2 tablespoons vegetable oil
1 package (4½ oz.) instant pudding
¾ cup nonfat dry milk powder

Stir milk and oil, add pudding mix and mix well. Pour into dishes of ½ cup servings.

TABLE 7

CALORIC DENSITIES OF SUPPLEMENTAL FOODS

FOOD	AMOUNT PER TABLESPOON	
	CALORIES	PROTEIN
BEVERAGES		
Juice	8	-
Infant Formula	10	.2
Whole Milk	10	.5
"Super" Milk	14	.9
Sustacal/Ensure	15	.9/.6
Fruited Yogurt	16	.5
Ice Cream	17	.1
Instant Breakfast (w/whole milk)	18	.9
Cream (½ and ½)	20	.5
Evaporated Milk (undiluted)	22	1.1
Ensure Plus	23	.8
Frappe	24	.8
Pudding	24	.6
PROTEINS		
Peanut Butter	94	4.0
Cheese	50	3.0
Dry Milk Powder	20	2.0
FATS		
Oil	125	-
Margarine	100	-
Mayonnaise	110	-
Gravy	26	.3
CARBOHYDRATES		
Honey	60	-
Karo Syrup	58	-
Jam, Jelly, Syrup	52	-
Chocolate Syrup, Sugar	45	-
Polycose/Moducal	23-30	-
Rice Cereal	9	.3

CONVERSIONS

1 oz=2 Tbsp
8 Tbsp=½ cup
16 Tbsp=1 cup
8 oz=1 cup
4 oz=½ cup
1 Tbsp=3 tsp

Failure to Thrive Clinic
Boston City Hospital
1985

Here's how to add extra Fluids & FIBER

1. Encourage your child to drink lots of liquids, offer juice, milk or water frequently.

2. Add 1 Tablespoon of bran a day to their foods. Slowly work up to 2 Tablespoons of bran daily. Put bran cereal in cereal, mashed potatoes, pureed foods or combined with hamburger.

3. Add a new fiber containing food daily from the list below. Serve up to 5 fibers foods everyday.

Fiber Foods

* Eat apples fresh or baked with the peel.
* Serve a green salad.
* Add bean sprouts to salads and sandwiches.
* Tomatoes have good fiber too.
* Try raw vegetable sticks. Cut up carrots, celery, cauliflower, zucchini, broccoli and eat them plain or with a dip.
* Squash is a good source of fiber baked or steamed.
* Add seeds and nuts for extra fiber - peanuts, sunflower seeds, sesame seeds, pumpkin seeds.
* Add dates raisins, and other dried fruits to foods.
* Use whole grain breads.
* Try oatmeal or wheatena for breakfast.
* Offer a small glass of prune juiceat breakfast or before bed.
* Popcorn adds fiber too.
* Cut whole organes and grapefruit into sections; eat them with part of the inner, white pith.
* Suprise! Cocoa has fiber too.

Fluids

HOW TO HELP YOUR CHILD ACCEPT FLUIDS

1 Offer small frequent sips of fluids.

2 Thicken fluids like soups, stews, milk and fruit juices by adding crackers to soups and stews or making a milk or fruit shake.

BANANA MILKSHAKE

1 cup milk
1 mashed banana
½ cup baby cereal

ORANGE SHAKE

½ cup orange juice
½ cup orange sherbert
¼ cup baby cereal

Does your child

refuse fluids?
need extra fluids?
have trouble swallowing fluids?

Here are some suggestions that may help.

3 Encourage eating of foods that become liquid at room temperature such as:

Fruit ice
Jello
Ice cream
Sherbert
Fruit juice Popsicles

4 Solid foods listed below contain fluids:

Commercially prepared Baby Foods
Yogurt
Custards
Junket
Pudding
Cottage cheese
Fruits & Vegetables (canned, frozen, fresh, cooked or raw)

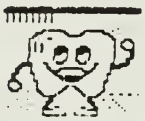
The recommended amounts of daily fluids are:

Child's weight	Total fluids needed in 24 hours
7 lbs.	2 cups
12 lbs.	3⅓ cups
21 lbs.	5 cups
26 lbs.	6 cups
36 lbs.	7 cups
44 lbs.	8 cups
63 lbs.	9½ cups
99 lbs.	10½ cups
119 lbs.	10½ cups

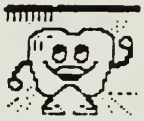
WATCH FOR SIGNS OF DEHYDRATION

Thirst
Loss of Appetite
Drowsiness
Flushed Skin
Increased Body Temperature
Increased Pulse Rate
Increased Breathing Rate

TABLE 9



DENTAL HEALTH



Healthy teeth are important for proper chewing, clear speech, and a pleasing appearance. Good dental care begins at birth when a parent should consciously decide not to put the infant to bed with a bottle in her mouth. Nursing bottle syndrome is caused by exposure of teeth to sugar for long periods of time. Bacteria normally present in the mouth interact with the sugar found in all liquids (except water) to produce a strong acid which decays the teeth. When a child sucks on a bottle all day long, or falls asleep with a bottle, her teeth are constantly bathed in a sugary solution and cavities begin. Cavities not only damage the teeth, but can be very painful and interfere with a child's normal eating, drinking and speech.

To prevent this condition from happening a parent should:

1 - Put only formula, milk, fruit juice or plain water in the bottle (no soda, punch, sweetened drinks)
2 - Give the bottle only at feeding time and hold and feed the child rather than propping the bottle with her in the crib
3 - Remove the bottle from the child's mouth if she falls asleep in your arms
4 - Do not dip the pacifier in sugar, honey, etc.
5 - Encourage the child to drink from a cup
6 - Practice good dental hygiene
7 - If a child must take a bottle to bed, allow plain water only

A child's baby or first teeth have an important role to play, even if some of them begin to fall out by the time the child is six or seven. The first teeth are used for support and shape of the face, in formation of sounds and words, for chewing, as spacing and proper alignment for the second or permanent teeth, and as shiny white components of a child's happy and endearing smile.

Once a baby's first tooth erupts, it should be gently wiped daily with a soft cloth, cotton swab or gauze to help remove any food residue. When the child has several teeth and is about one year old, a small, soft toothbrush can be introduced and encouraged. Children love to imitate and will eagerly brush their teeth along side of a parent or sibling. If a child cannot handle a toothbrush and is resistant to allowing someone else to brush her teeth, she can chew on a cellulose sponge coated with a little toothpaste. If poor hand to mouth coordination is a problem, an electric toothbrush might be helpful. In either case, proper

supervision is needed. Fluoride toothpaste can be introduced in small amounts, when the child is about 18 months old. Toothpaste should not be swallowed because it contains a lot of sodium.

By avoiding sticky, sweet foods, we can cut down on the amounts of residue left on the teeth. Raw fruits and vegetables have been referred to as nature's own toothbrush, as chewing of these foods helps to remove food particles left on and in between the teeth.

A visit to the dentist should be arranged when the child reaches her third birthday. By promoting good dental care, we can provide years of healthy, disease free teeth.

FLUORIDE

Fluoride has been proven effective in preventing tooth decay, and many communities have added it to their drinking water. Fluoride is a mineral that helps to strengthen bones and teeth, and is found in small amounts in some foods. Adding fluoride to the water supply is a controversial issue, and at present fluoride is not added to the New Bedford water. Parents should consult with their doctor or dentist and follow their recommendations for fluoride supplementation. Fluoride found in toothpaste or in mouth rinses is topical and wears away quickly. It should not act as a substitute for fluoride supplements prescribed by the doctor.

SUGAR

Most people think of candy, chocolate, soda, pies, cakes and other desserts when the word sugar is mentioned. Today, sugar is added to many food products and it is estimated that the average American consumes well over 100 pounds of sugar per year.

Did you know that...

...some soft drinks (soda) contain 10 or 12 teaspoons of added sugar per 12 ounce can?

...one chocolate candy bar contains 8-12 teaspoons of added sugar?

...fruit punch or fruit drinks (not 100% juice) contain 6-8 teaspoons of added sugar per glass?

...some of the most popular children's breakfast cereals are anywhere between 40-50 even 60% sugar? Are we really

giving our kids candy for breakfast?

...a frosted doughnut contains about 8 teaspoons sugar?

...one stick regular gum contains 1/2 teaspoon sugar?

Read your catsup bottle, your jar of spaghetti sauce, your can of soup, your bag of frozen potato puffs, and even your box of salt. Look through the list of ingredients in a packaged salad dressing, or a frozen dinner. Sugar is everywhere, although it may be called dextrose, sucrose, fructose, corn syrup, corn syrup solids, malto-dextrin, etc.

Sugar does supply calories but it does not supply any of the other nutrients the body needs and often contributes to dental cavities, excessive weight gain and can also cause increased drooling. Sugar can satisfy that sweet tooth craving and can add needed calories for someone trying to gain weight, but sugared foods should not be used for rewards or incentives to eat or perform specific tasks. Intake should be limited.

TABLE 10

Drugs & Diet

Conditions common to the developmentally delayed child are likely to necessitate long-term or prolonged treatment with drugs.

THE effects of drug therapy on your child's nutritional status are important.

WHEN USING	CONSIDER	BECAUSE it may cause
Anticonvulsants		
Dilantin Phenobarbital Depakene	Taking right after meals. Vitamin D supplement. Good oral hygiene.	Decreased absorption of vitamin B^{12}, D, calcium & folate. Nausea, vomiting, loss of taste, gum irritation with long-term use.
Antibacterial Agents (for prevention/treatment of urinary tract infections)		
Furadantin Bactrim/Macrodantin	Giving with meals.	Nausea, vomiting, abdominal pain, diarrhea.
Central Nervous System Stimulants		
Dexedrine	Giving with meals.	Anorexia (loss of appetite), abdominal pain.
Laxatives		
Colace Mineral Oil	Administering with milk or juice. Taking before bedtime.	Bitter taste, nausea, vomiting. Decreased absorption of fat soluble vitamins, possible flatulence, indigestion.
Tranquilizers/Muscle Relaxants		
Valium Theophylline Thorazine	Increasing fluid intake. A high fiber diet.	Drowsiness, nausea, changes in salivation, possible constipation.
Antibiotics		
Tetracycline	Taking 1 hr. before or 2 hrs. after meals. (Do not take with dairy products).	Nausea, loss of appetite, decreased iron absorption, diarrhea.
Erythromycin	If coated, giving with meals.	

COMMUNICATION: OLD AND NEW METHODS

Objectives

After completing this unit, participants will:

1. Describe the diagnostic parameters concerning communication issues and the child who has a severe disability.

2. Discuss various practical concerns relative to personal, social and environmental communication needs of the child.

3. Distinguish between augmentative and alternative communication modes.

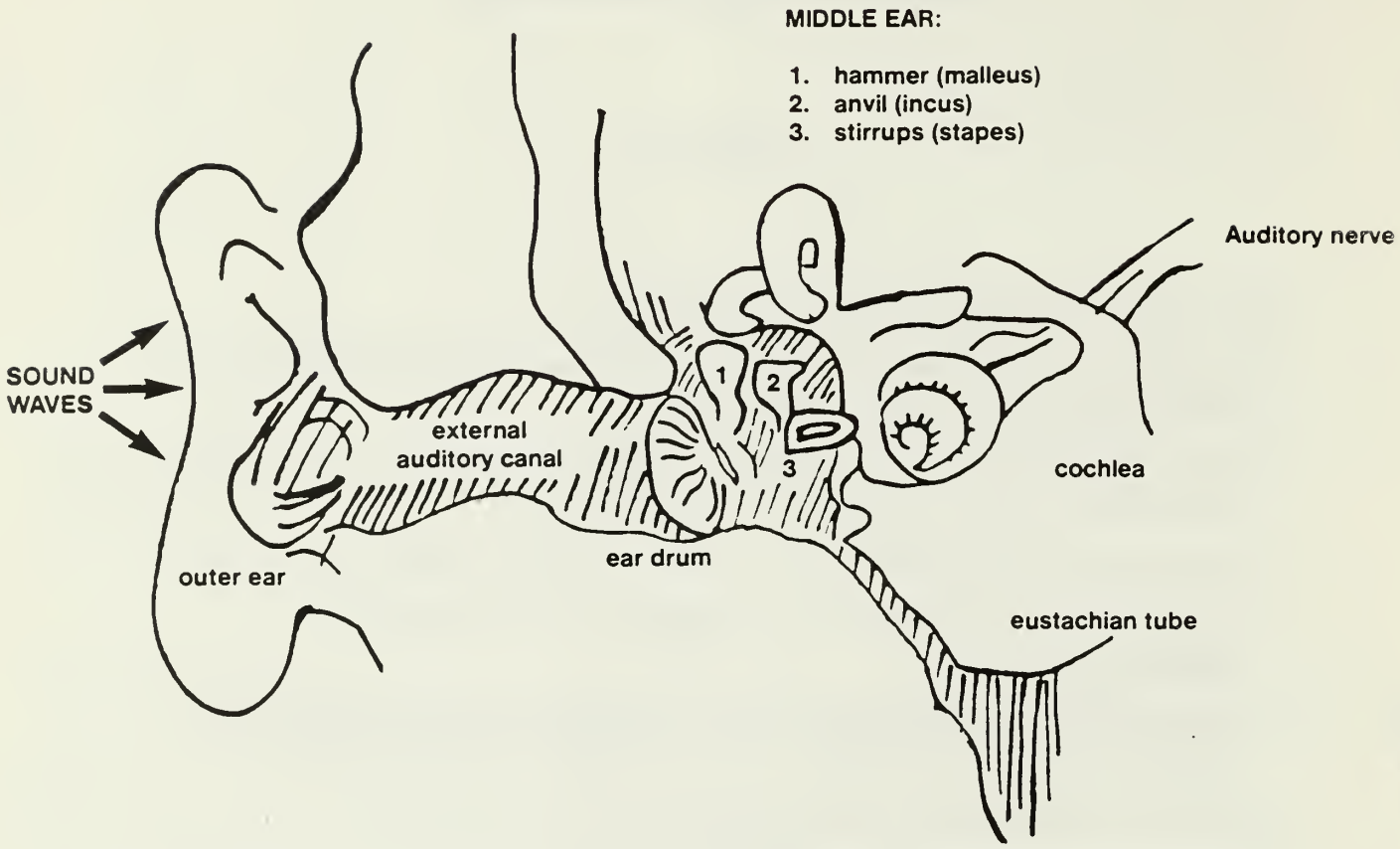
4. Become familiar with the use of augmentative and alternative communication systems.

5. Explain the profound implications of hearing loss and recognize the importance of positive models and strategies for intervention.

6. Describe a total communication approach and environment.

7. Demonstrate the use of available technology.

COMPONENTS OF HEARING



Components of Hearing:

Between receiving a sound and processing and "decoding" the sound, several transitions happen:

SOUND WAVES
(to outer ear)

↓

"MECHANICAL" VIBRATION
(middle ear)

↓

"HYDRAULIC" VIBRATION
(cochlea)

↓

"ELECTRICAL" IMPULSES

↓

SOUND IS PROCESSED
(brain)

Hearing Impairment

OVERVIEW AND INTRODUCTION

- Indications of Hearing Loss
- Diagnosis
- Kinds of Hearing Loss

IMPLICATIONS OF HEARING LOSS

- Communication
- Language Development
- Psycho-Social Development
- Cognitive Development
- Educational Achievement

INTERVENTION MODELS

"Deficit" model

- Clinical/medical model
- "Pathologizing of deafness"
- Primary focus and concentration on the disability and its correction
- "Normalizing" goal using one model for "normal"

"Difference" model

- Social/cultural model
- "Depathologizing of deafness"
- Primary focus and concentration on the whole child and his/her development
- "Normalizing" goal using alternative models for "normal"

(continued)

INTERVENTION STRATEGIES

"Oralism" or Oral Focus

- Definition
- Strategies re: implications of hearing loss
- Parent and professional roles
- Issues re: attitudes toward hearing loss

Total Communication

- Definition
- Strategies re: implications of hearing loss
- Parent and professional roles
- Issues re: attitudes toward hearing loss

EDUCATIONAL OPTIONS

Early Intervention/Parent-Infant Programs

- Availability
- Crucial intervention issues

School Placement Options

- Private school for the deaf
- Collaborative program
- Local school district program: classes and individual placement
- Resource room

ASSISTIVE LISTENING DEVICES/AVAILABLE TECHNOLOGY

Kinds/Uses of Listening Devices

Kinds/Uses of Available Technology

Educational Implications

Social/Cultural Implications

ASSESSMENT OF COMMUNICATION COMPETENCIES

Introduction

In assessing the speech and language status of the nonvocal child, it is paramount to view the parameters of communication as systematically-related rather than as isolated areas of study.

Areas of Consideration

Reception of Language

-Understanding of gestures

-Understanding of pictures/symbols

-Understanding of spoken words (semantics)

-Understanding of verbal language

-Understanding of written language

Storage (memory, categorization) of language

Associative reasoning

Expression of Language

-Gestural - imitative/spontaneous

-Verbal - imitative/spontaneous

-Functional value of gestures/verbalizations

-Written expression

-Strategy formulation

Intent/Need for Communication

-Spontaneous

-Responsive

Trained/Creative

Feasibility of System(s)

Means of Assessment

Area	Test	Task

-Semantics (vocabulary)

-Morphology (word form)

-Syntax (word order)

-Strategy Generation/Problem solving

-Memory

Type -immediate, short term, long term
Mode -auditory, visual, tactile, multi

COMPLIMENTARY CONSIDERATION

Peripheral Auditory Acuity

Central Auditory Competencies

-Selective attention (figure-ground discrimination)

-Attention/concentration vigilance

-Phonemic/whole word discrimination

-Sound/symbol association

Peripheral Visual Acuity

Central Visual Competencies

-Symbol discrimination

-Object-symbol constancy

-Scanning/rate

-Attention/concentration vigilance

General Physical/Emotional Status

Educational Impact:

General Classroom Performance: attending
direction following
memory
vocabulary repertoire

Reading/Spelling

Mathematics

Treatment

Teaching of skills vs. teaching of strategies

UTILIZING AUGMENTATIVE AND ALTERNATIVE NON-VOCAL

COMMUNICATION SYSTEMS

Introduction

When considering the use of a non-vocal communication system, we should keep in mind the following four parameters in order to assure for optimal performance and utilization:

1. Clarity of syste
2. Ease of operation/care
3. Flexibility
4. Personal perceptions

Gestural (An introduction to formal and informal modes of facial and manual communication sytems)

Language Boards

Electronics Devices

Environmental Systems

BIBLIOGRAPHY

Beukelman, D. et al. Communication Augmentation: A Casebook of Clinical Management. College-Hill Press, San Diego, California, 1985.

Calculator, S. and C. Dolloghan, The Use of Communication Board in a Residential Setting: An Evaluation, Journal of Speech and Hearing Disorders, 47, 281-287, 1982

Musselwhite, C. and K.St. Louis, Communication Programming for the Severely Handicapped: Vocal and Nonvocal Strategies. College-Hill Press, San Diego, CA 1982

Schiefelbusch, R. Non-Speech Language and Communication Analysis and Intervention. University Park Press, Baltimore, MD, 1980

Silverman, F., Communication for the Speechless. Prentice-Hall Press Englewood Clifts, NJ, 1980

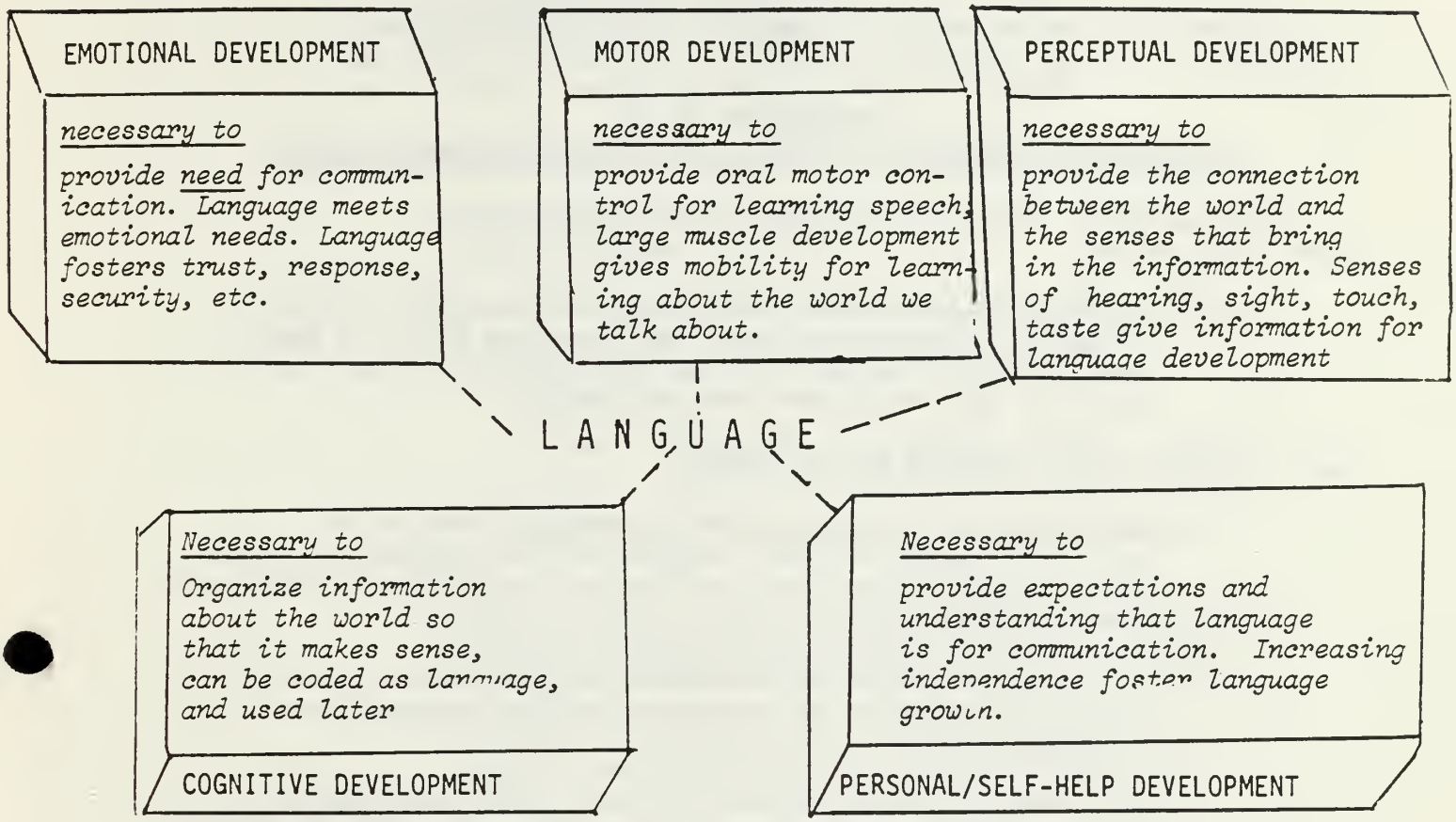
Vanderheiden, G., Nonvocal Communication Resource Book. University Park Press, Baltimore, MD. 1978

Vanderheiden, G., Selection and Application of Microcomputers for Handicapped Individuals. University of Wisconsin, Madison, WI, 1982

Vanderheiden, G., and Grilley, K., Nonvocal Communication Techniques and Aids for the Severely Physically Handicapped. University Park Press, Baltimore, MD, 1978

FOUNDATIONS OF LANGUAGE DEVELOPMENT

Language development occurs naturally and in relation to other areas of growth and development. The following illustrates how language is built upon other foundation blocks:


EMOTIONAL DEVELOPMENT
necessary to
provide need for communication. Language meets emotional needs. Language fosters trust, response, security, etc.
MOTOR DEVELOPMENT
necessary to
provide oral motor control for learning speech, large muscle development gives mobility for learning about the world we talk about.
PERCEPTUAL DEVELOPMENT
necessary to
provide the connection between the world and the senses that bring in the information. Senses of hearing, sight, touch, taste give information for language development
LANGUAGE
Necessary to
Organize information about the world so that it makes sense, can be coded as language, and used later
COGNITIVE DEVELOPMENT
Necessary to
provide expectations and understanding that language is for communication. Increasing independence foster language growth.
PERSONAL/SELF-HELP DEVELOPMENT

Since language depends on so many other areas of development, it is no wonder that it is quite a common area to show delays or problems. Children with speech and language delays are among the greatest numbers of handicapped children that the teacher in a mainstreamed setting will encounter. Language delays or more long-lasting impairments can be present in children who have other special needs, such as mental retardation. Or it can be the child's only special need, as in the child with a language learning dis-disability.

The Commonwealth of Massachusetts
Executive Office of Human Services
Massachusetts Commission for the Deaf and Hard of Hearing

Description of the
Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)

What is the MCDHH?

- The Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH) is a commission, under the Executive Office of Human Services, which serves as the principal agency in the state on behalf of deaf and hard of hearing people.

What are the primary mandates for the MCDHH?

- The Commission was established to advocate, provide and coordinate public policies, regulations and programs to provide full and equal opportunity for deaf and hard of hearing people in Massachusetts.

- The MCDHH is also mandated to improve accessibility and quality of existing services and promote or deliver necessary new services.

- The Commission is mandated to increase public awareness and to determine the extent and availability of services, determine the need for further services, and make recommendations to the Governor.

What services and programs does the MCDHH offer?

- Interpreter Services maintains and coordinates a statewide sign language interpreter referral service for deaf and hard of hearing persons; screens and approves potential interpreters; provides information regarding interpreter services, evaluations and certifications; and supports training of interpreters.

- Fund for Purchase of Interpreter Services: pays for interpreter services for many types of events in which other agencies are not legally responsible to pay.

- Information Services provides public education, accessibility training, fact sheets, a newsletter and speakers.

- TDD Distribution Program rents or sells at a discount TDDs (TTYs) to eligible residents of Massachusetts who apply.

continued ... next page

- The Case Management Program provides cross-agency case coordination and technical assistance, referrals to other agencies, and assistance to deaf and hard of hearing individuals with complex life situations. It also provides Chapter 688 Transitional Case Management services.

- Program Development and Special Services: MCDHH is engaging in development of needs assessments, information and consultation in the areas of: early intervention, education, housing, employment and special services for hard of hearing persons.

- Contracted Services:

    - Independent Living Programs for Deaf and Severely Hearing Impaired People located at:

        Ad-Lib Center for Independent Living, Inc., Pittsfield

        Center for Living and Working, Worcester

        D.E.A.F., Inc., Allston

        Northeast Independent Living Program, Inc., Lawrence

        Southeast Center for Independent Living, Fall River

        Stavros Center for Independent Living, Springfield

    - Public Education Program on Assistive Listening Devices and Other Communication Devices for Hard of Hearing People, through the Boston Guild for the Hard of Hearing.

    - Statewide Massachusetts TTY/Telephone Message Relay Service located at D.E.A.F., Inc. in Allston.

Where are the MCDHH offices?

- Boston Home Office and Eastern Massachusetts Regional Services:

  Massachusetts Commission for the Deaf and Hard of Hearing
  600 Washington Street, Suite 600
  Boston, MA 02111
  (800) 882-1155 V/TDD
  (617) 727-5106 V/TDD

- Central Massachusetts Regional Office:

  Massachusetts Commission for the Deaf and Hard of Hearing
  22 Front Street
  P.O. Box 8210
  Worcester, MA 01614
  (617) 755-4084 V/TDD

- Western Massachusetts Regional Office:

  Massachusetts Commission for the Deaf and Hard of Hearing
  1694 Main Street
  Springfield, MA 01103
  (413) 788-6427 V/TDD

PHILIP W. JOHNSTON
SECRETARY
BARBARA JEAN WOOD
COMMISSIONER

The Commonwealth of Massachusetts
Executive Office of Human Services
Massachusetts Commission for the Deaf and Hard of Hearing

FINANCIAL ASSISTANCE FOR HEARING AIDS *

This listing of available sources of financial assistance toward the purchase of a hearing aid is prepared as a public service of the Massachusetts Commission for the Deaf and Hard of Hearing. The list is provided for informational purposes only, and does not imply endorsement by the Commission.

o **PUBLIC AGENCIES**

DEPARTMENT OF PUBLIC HEALTH
Hearing Aid Program
150 Tremont Street, 3rd Floor
Boston, MA 02116
(617) 727-2682 TDD
(617) 727-0944 Voice

Children with any type of hearing loss, ages 0-21, may receive assistance, depending upon financial eligibility. They must receive an audiological evaluation and hearing aid recommendation through a center approved by the Department of Public Health. The program covers insurance for the aid and any necessary repairs.

DEPARTMENT OF PUBLIC WELFARE
Medicaid Program
600 Washington Street, 5th Floor
Boston, MA 02111
(617) 348-5362 Voice
Contact: Gail DeRosa

The Welfare Office of Client Service can provide information about all aspects of Welfare, including Medicaid, and can also be contacted at:
(617) 574-0232 TDD
(617) 574-0450 Voice

Persons on Medicaid are generally eligible for free hearing aids. Recipients may contact local welfare offices for information about correct procedures and requirements for obtaining hearing aids. The central office may be contacted for questions about eligibility and policies, and the location of local offices

Brighton Marine Public Health
77 Warren Street
Brighton, MA 02135
(617) 782-6136 Voice
Contact: Mary Magowan for retired military personnel matters.

Dependents of active duty military personnel can apply for financial assistance under the Handicapped Program. With prior approval from CHAMPUS, financial assistance is provided for hearing aids and other medical needs up to $1000 a month.

Retired military personnel may receive free hearing aids. They must first have a hearing evaluation by a certified audiologist at the clinic.

o NON-PROFIT AGENCIES

BOSTON GUILD FOR THE HARD OF HEARING
283 Commonwealth Avenue
Boston, MA 02115
(617) 267-3496 TDD
(617) 267-4370 Voice
Contact: Sheila Schulman

Clients of the Boston Guild for the Hard of Hearing may receive limited financial assistance for hearing aids, based on income. The Guild will make referrals if it cannot provide financial assistance to a client.

NATIONAL CHILDREN'S HEARING AID BANK
The Children's Hearing Foundation
220 South 16th Street
Philadelphia, PA 19102
(215) 735-5675 Voice
Contact: Beverly Hoffmann

Children ages 0-18 who need amplification but have been refused assistance from governmental and private agencies may obtain assistance from this organization. There must be written documentation of refusal before the request will be considered; an audiological evaluation is required.

o INSURANCE COMPANIES

BLUE CROSS & BLUE SHIELD
100 Summer Street
Boston, MA 02110
(617) 956-3801 TDD (state employee plan)
1-800-441-5588 Voice (state employee plan)
Contact: Susan Capelotti

Individual Blue Cross & Blue Shield policies (those not offered by place of employment) do not provide hearing service benefits.

Massachusetts state employees may receive approximately 80% of allowed charges for the initial purchase of a hearing aid (not including the fitting and dispensing, battery and repair charges), and not to exceed $450.00 per calendar year. Other holders of group policies should contact their workplace personnel office. HMO members should telephone their health plan offices.

o HMOs (HEALTH MAINTENANCE ORGANIZATIONS) **

COMMUNITY HEALTH PLAN
Hillcrest Family Health Center
Hillcrest Hospital
165 Tor Court
Pittsfield, MA 01201
(413) 499-2051, Ext. 52 Voice

Members of the Community Health Plan (CHP) may be eligible for financial assistance for hearing aids, depending on the type of plan they select. CHP serves members in central and western Massachusetts, eastern New York and southern Vermont.

RHODE ISLAND GROUP HEALTH ASSOCIATION
2 Davol Square
Providence, RI 02903
(401) 421-4410 Voice
Contact: David J. Dennis

Members of the Rhode Island Group Health Association may be eligible for financial assistance depending on the type of plan they select. The Rhode Island Group Health Association serves members in all of Rhode Island and southeastern Massachusetts.

MASSACHUSETTS REHABILITATION COMMISSION
Statler Office Building
20 Park Plaza, Room 1136
Boston, MA 02116
(617) 727-9854 TDD/Voice
Contact: Lois Willett

Clients of Massachusetts Rehabilitation Commission may receive restorative services such as hearing aids. Services are provided to persons who need them to secure or retain gainful employment.

MASSACHUSETTS COMMISSION FOR THE BLIND
110 Tremont Street
Boston, MA 02108
(617) 727-5550 TDD/Voice
Contact: Christine McLaughlin

Persons may be eligible for financial assistance for hearing aids under the Massachusetts Commission for the Blind's Medicaid Program or its vocational rehabilitation program. They can receive financial assistance from the Medicaid Program: if they are eligible to receive Supplemental Security Income (SSI) for the Blind or if they are eligible for medical assistance only. If persons are ineligible for Medicaid, the Commission determines if its vocational rehabilitation program can provide financial assistance. Determination is based on an applicant's income and savings.

U.S. VETERANS ADMINISTRATION
Veterans Administration Outpatient Clinic
Audio-Speech Pathology Service
17 Court Street
Boston, MA 02108
(617) 565-9400 Voice
Contact: Dr. Schill and staff

All World War I veterans, former Prisoners of War (POWs), veterans with service-connected hearing disabilities or veterans who are 50 percent or more disabled as a result of service-connected disabilities may be eligible for hearing aid services. Veterans who consider themselves eligible should contact Veterans Administration and ask for an eligibility clerk.

CHAMPUS (CIVILIAN HEALTH AND MEDICAL PROGRAM UNIFORMED SERVICES)
Cutler Hospital
Fort Devens, MA 01433-6401
(617) 796-6875 Voice
Contact: Doris Stone for dependents of active duty personnel matters.

o CIVIC AND COMMUNITY ORGANIZATIONS

Persons not covered by any of the above may try contacting various service agencies in the community such as the Lions, Rotary, Kiwanis or Quota Clubs (the Quota Club is especially interested in hearing loss). On occasion, these organizations will purchase hearing aids, TDDs, and other types of specialized equipment for hearing impaired persons. Decisions are made on an individual basis.

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* The Department of Public Health, Department of Public Welfare, Massachusetts Rehabilitation Commission, Veterans Administration, Blue Cross & Blue Shield, Community Health Plan and the civic organizations listed have many local offices and branches. Contact the sources listed for information about other addresses and telephone numbers.

** To the best of MCDHH's knowledge, only the HMOs listed provide financial assistance for hearing aids. Members should check with their local HMOs for information.

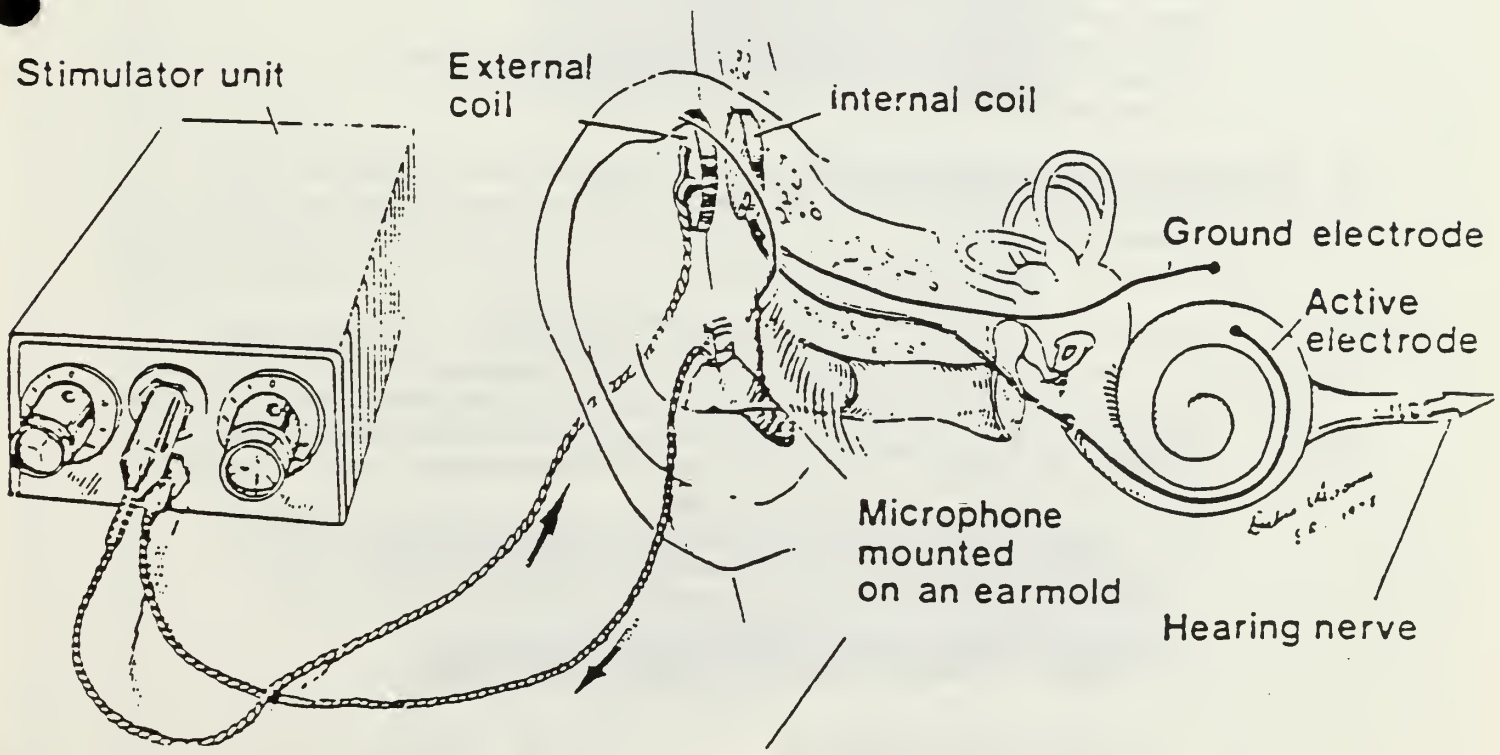
AS:RW:JR 5-87

ACTION ALLIANCE of PARENTS of the DEAF
120 W. Lancaster Avenue Ardmore, PA 19003

-The cochlear implant research program requires that subjects return every year for audiologic, medical, and psychological evaluations for as long as they use the implant.

PLEASE NOTE: Most children who have received cochlear implants remain in Total Communication programs for the deaf and hearing impaired. These children, even though they can hear some environmental sounds, still require a visual sign system to help them develop language.

Cochlear Implant System



Developed for Project Hope 1984 by Barbara Murray, former Research Assistant in the University of Pennsylvania Cochlear Implant Program.

ACTION ALLIANCE of PARENTS of the DEAF
120 W. Lancaster [illegible] Ardmore, P[illegible] 19003

FACTS ABOUT THE COCHLEAR IMPLANT

A. You may see the implant called by other names:
- Ineraid
- Extracochlear Implant
- Bionic Ear
- Artificial Ear
- Miniature Ear Radio

B. What is the implant?

It is an electronic device for people with a profound hearing loss who receive NO HELP from hearing aids. The implant sends an electronic signal to the cochlea, this signal effects the hearing nerve and results in the perception of sound.

A person with a chchlear implant can hear environmental sounds, but he/she WILL NOT BE ABLE TO UNDERSTAND SPEECH.

C. The cochlear implant consists of two parts (refer to the picture):
1. The internal part which is surgically implanted in the ear.
2. The external part resembles a body hearing aid.

D. Benefits of the Cochlear Implant (based on adult research)
- -Subjects can hear (but NOT understand) environmental sounds.
- -May have a decrease in ear noises and dizziness.
- -Help to improve lip reading skills.
- -Users can monitor voice levels more easily.
- -Subjects feel safer because they can hear warning sounds in the environment.

E. Limitations of the Cochlear Implant
- -Benefits are based only on ADULT research.
- -Risks of surgery:
  - a) infection
  - b) facial paralysis
  - c) taste disturbance and mouth dryness
  - d) fluid drainage resulting in meningitis
  - e) possible increase in ear noise or dizziness
- -Users still cannot understand speech through audition alone.
- -Sounds heard are described as like "Donald Duck's voice"
- -Coil alignment may be difficult-must shave area daily
- -Cost is prohibitive - $15,000-$20,000
- -LONG TERM EFFECTS OF ELECTRICAL STIMULATION OF THE BRAIN AND COCHLEA ARE UNKNOWN! THE COCHLEAR IMPLANT IS AN EXPERIMENTAL DEVICE WHICH IS MONITORED BY THE FOOD AND DRUG ADMINISTRATION (FDA).
- -IT WILL NOT MAKE A DEAF PERSON HEARING!

The Commonwealth of Massachusetts
Executive Office of Human Services
Massachusetts Commission
for the Deaf and
Hard of Hearing

PHILIP W. JOHNSTON
SECRETARY

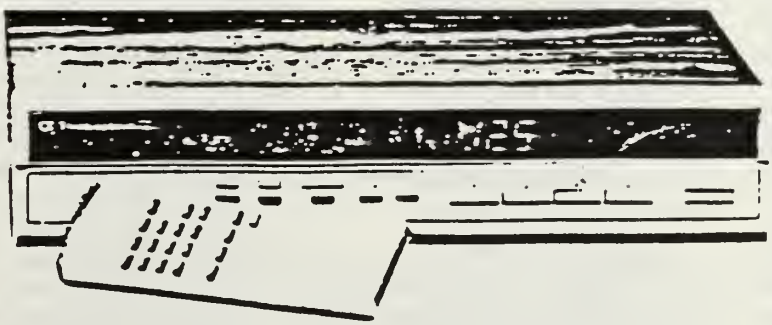
BARBARA JEAN WOOD
COMMISSIONER

WHAT IS A TELECAPTION ADAPTER (or DECODER)?

A TeleCaption TV Adapter puts closed captions, or "subtitles" on any television set: color or black and white, old or new, large or small. These captions are easily visible--usually white letters against a black background--and usually appear at the bottom of the screen.

The TeleCaption Adapter will display captions for any closed-captioned program or home video movie. The Adapter will not interfere with the regular workings of your TV and will in no way harm it. It can even improve television reception!

The Adapter also works with cable TV, videocassette recorders and videodisc players. The new TeleCaption Adapter II (pictured below) is easier to hook up, more attractive, cable-ready and includes remote control capability. It is also smaller, lighter in weight, easier to transport and has a digital readout panel.



PLEASE NOTE!! The purchase price of TeleCaption Adapters can be deducted as a medical expense according to IRS Ruling #80-340.

SUITE
BOSTON, MA 02

What are TDDs?

A FACT SHEET
FROM THE
NATIONAL INFORMATION
CENTER ON DEAFNESS,
GALLAUDET COLLEGE

Effective communication is a vital element of daily living. In all areas of our personal and our professional lives, an important component of communication today is the ability to use the telephone. In fact, we take the use of this familiar device for granted.

It is only in very recent years, however, that this twentieth century convenience has become available to the more than 16 million hearing-impaired citizens in our society. Because of technology and research, it is now possible for the hearing-impaired population to communicate via the telephone through special assistance devices.

Recent federal legislation, coupled with awareness by the general public and advocacy groups, has encouraged increased usage of reasonable telecommunications accommodations for the hearing-impaired community. TDD devices are becoming familiar apparatus in public places nationwide — in hospitals, airports, police stations, hotels, libraries, public agencies and private companies, physicians' and lawyers' offices, and on college campuses. Several of the nation's major corporations include the purchase of TDDs in their benefit programs for their hearing-impaired employees. And, TDD equipment is being linked to computers to assist in relaying information from a myriad of sources through an electronic information network.

This fact sheet is a broad overview of telecommunication devices for hearing-impaired people. The information contained here is provided as a guideline only. Included is some helpful information to consider when purchasing a TDD, some facts on how to assess needs and usage, and some interesting TDD facts and data. Additionally, a listing of current companies and different TDD models manufactured is available from the National Information Center on Deafness.

WHAT IS A TDD? A TTY?

A TDD (Telecommunications Device for the Deaf) is a device which allows a deaf individual to make a telephone call directly, without the use of another person to interpret. The conversation is typed rather than spoken. Both parties in the conversation must use a TDD and the devices must be compatible.

The term TTY is often used interchangeably with the term TDD; however, this term refers to the original mechanical teletypewriter equipment specifically. Teletypewriters (TTYs) are still in use — both the old and much newer models — and the term TTY should be used to refer to this specific kind of equipment.

WHO USES TDDs?

TDD accessibility makes direct and private communication possible for deaf consumers who, in the past, had to rely on family members or friends to complete calls for them. Hearing-impaired individuals, their families, and their friends are the primary users of TDDs. Additionally, a growing number of government agencies, corporations, private organizations, and public institutions are installing TDDs in order to provide direct phone communication to and for their deaf constituents, clients, and customers.

TDD 1

TDD Keyboard Language

TDD users use several abbreviations in their communiques:

GA	Go ahead
SK	Bye Bye
HD	Hold on
PLS	Please
OIC	Oh, I see
CUL	See you later
U	You
Q	Question?

It is considered polite always to end a conversation with a "Goodbye," or "So long," or "Thanks again," prior to signing off and before you type "SK."

HOW DO YOU USE A TDD?

TDD messages are typed rather than spoken.

▸Placing a TDD call:
The calling party dials the telephone in the usual way, places the telephone receiver in the cradle or modem of the TDD, and then watches a monitor light on the TDD. From the pattern of flashes, the calling party can identify a busy signal, a ringing telephone, or an interruption in the pattern when a call has been answered. When the calling party types out a message on a TDD which is equipped with a regular typewriter keyboard, the receiving party reads the message on the built-in screen or paper print-out of the TDD.

▸Receiving a TDD call:
TDD devices owned by deaf individuals are usually equipped with a special flashing light which alerts the owner to an incoming telephone call. The individual anwers by placing the handset of his or her telephone into the cradle of the TDD instrument, turning the switch to "on", and typing out an identification greeting such as: "[illegible], is Mary Smith, good morning, GA." The caller responds with his or her name and greeting, and the conversation proceeds.

WHAT ARE SOME TDD EQUIPMENT FEATURES?

TDDs have the following basic features:

▸Keyboard: All TDDs have a keyboard which resembles that of a small typewriter. Some keyboards use four rows of keys; others use only three rows.

▸Display - Hard/Soft Copy: Essentially, there are two methods of transmitting conversations between individuals communicating on a TDD. A "soft-copy" TDD is one with a display screen on which the typed message appears electronically as it is typed. The display screen can be incorporated within the TDD itself either as a CRT screen or single-line display or it can be a separate display unit (a TV screen) connected to the TDD equipment. For individuals with a need for a permanent record of a given conversation, other TDD devices are available which are equipped with a roll of regular or special paper. The message is printed on the roll and can be preserved. This is referred to as a "hard-copy" TDD.

▸Portability: Portability may be an important consideration in the purchase of TDD equipment. TDDs vary in size, weight, and power requirements. Although some TDDs will easily fit into an attache case, most have specially designed carrying cases. And, most TDDs have the capability of operating either on a standard electrical outlet or on an incorporated battery pack.

ARE THERE OPTIONAL FEATURES?

▸Telephone Signaller Device: Many deaf individuals depend on a flashing light to alert them to incoming calls. A telephone signaller is a device that is sensitive to sound and into which a lamp can be plugged. When the signaller is placed near the telephone, each ring will cause the lamp to flash. Telephone signallers are usually available as a separate accessory from either the local telephone company, from various manufacturers, or from authorized TDD dealers.

▸Memory: Some TDD manufacturers offer a built-in memory unit; others provide it as an optional attachment. TDDs with memory capability can be used to store short messages or selected portions of a conversation for later reference. It is also possible to compose a message in memory prior to placing the call and then transmit the message later after phone contact has been made. This may be useful when one wishes to send the same message to several people; it can also save costs on a long-distance call.

WHAT CONSIDERATIONS SHOULD BE MADE WHEN PURCHASING A TDD?

Most people can easily recall the purchase of their first new car. Generally, a survey of dealerships, discussion with salespersons, and an evaluation of performance features as well as styling and color choices contributed to the purchase decision. Purchasing a TDD should not be unlike this or any other major purchase decision.

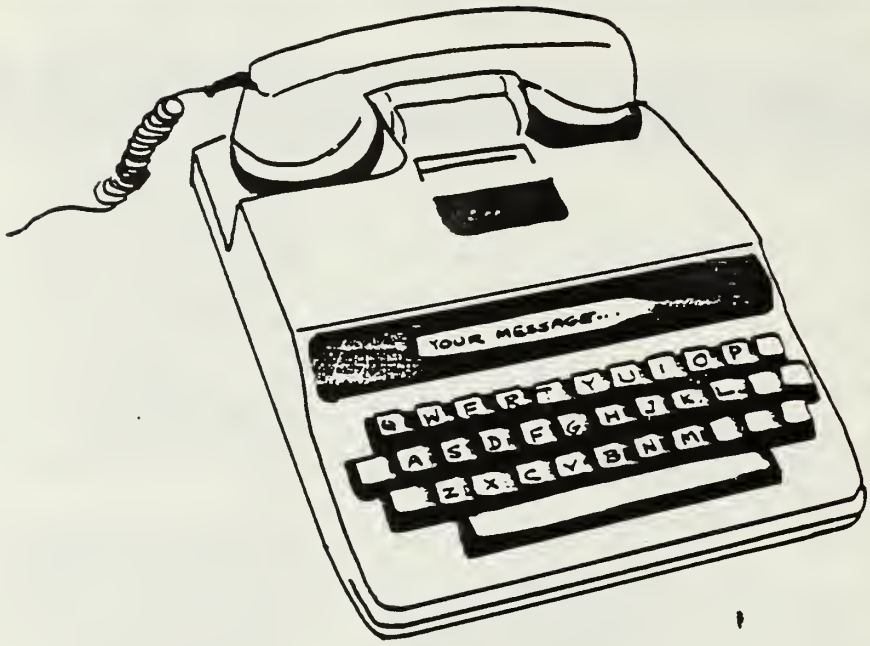
As a consumer, you should become informed, assess your personal needs and expectations, investigate available models and equipment options, and then, based on this information, make the purchase.

Essentially, the following should be considered:

▸Price: TDD manufacturers have varying price structures. A product survey by the consumer, coupled with

one's individual price restrictions, will determine the most appropriate manufacturer and model.

- ▸Size/Space: Although the majority of TDD equipment is portable, large, permanently installed, converted teletypewriters, in addition to new floor models, are also available. Such equipment may often be seen in public places, schools, and offices. Approximately three cubic feet of space is needed to install this type of TDD. Portable equipment is lightweight, is accessible for use at home, in the office, or from a hotel room or public phone when traveling, and can be carried in a specially designed case.
- ▸Hard copy vs. soft copy: The choice between a hard-copy TDD and a soft-copy TDD will depend on the individual consumer's needs. Purchase of a hard-copy TDD model will provide the consumer with the availability of a permanent record of all telephone calls. This is especially important to consider in a business setting where there is a high volume of telephone activity. If you opt for a soft-copy model, you will have to choose further between a variety of models that offer different sized display screens and size and color of print-out capability. Depending on the manufacturer, output characters range in size from ¼ to ½ inch in height and may appear in either red, green, or blue on the display screen.



Did You Know?

There are 498,104,000 telephones in the world.

There are 180,425,00 telephones in the USA.

There are 80,000 TDDs in use nationwide.

The average American makes 1,128 telephone calls per year, or approximately three telephone calls per day.

There are approximately 50 "800" numbers for TDD subscribers.

There are over 100 special TDD emergency numbers.

Forty-three states offer reduced rates, both intra-state and inter-state to TDD customers.

- ▸Optional equipment: A variety of accessories are available with most models and manufacturers. Some of the more common ones are:
  - Telephone Signaller Device
  - Rechargeable Battery Pack
  - TDD Carrying Case
  - Memory Capability (built-in or attachment)

TDD PURCHASE GUIDELINES

Here are some tips on how to get started with the purchase of a TDD.

> Contact the manufacturer or authorized agent/dealer and make an appointment.

> Ask questions: How long has the company conducted business? Location of service centers? What is the warranty/guarantee period? What is covered? What are service procedures?

> Receive a demonstration of the product.

> Read the instructions and product literature.

> Consider the price.

INFORMATION RESOURCES

Telecommunication Devices for the Deaf:

An excellent source of information is an organization called Telecommunications for the Deaf, Inc. (TDI). This organization oversees consumer matters related to telecommunications for deaf people. TDI publishes an annual directory which lists membership subscribers in seven categories: residential, business, professional, religious, emergency, government, schools and colleges. An up-to-date listing of TDI approved agents/dealers in your area of the country is available upon request. Additionally, TDI is an information source on current TDD manufacturers and equipment.

TDI can be contacted at:
814 Thayer Avenue
Silver Spring, Maryland 20910
TDD/Voice (301) 589-3006

Deafness and Deaf People:

Deafness has often been referred to as the "invisible" disability. In recent years, through research, education, and acceptance of different modes of communication, deaf individuals have been successful in making notable contributions to their individual chosen fields of endeavor.

Parents, professionals, students, and interested consumers can find out about the varied aspects of deafness including education, communication methods, and national deafness-related organizations by directing questions to the following sources of information:

The National Information Center on Deafness
Gallaudet College
800 Florida Avenue, N.E.
Washington, D.C. 20002
TDD/Voice: (202) 651-5109

The National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910
TDD/Voice (301) 587-1788

The Alexander Graham Bell Association
3417 Volta Place, N.W.
Washington, D.C. 20007

This fact sheet was prepared by Kay Fitzgerald, who is currently on assignment to Gallaudet College from the IBM Corporation Faculty Loan Program. Gallaudet College is an equal opportunity employer/educational institution. Programs and services of Gallaudet College receive substantial financial support from the Department of Education.

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Telecommunications Devices for the Deaf (TDD) Equipment Manufacturers

The following companies manufacture TDD equipment for hearing-impaired people. You are advised to contact the companies directly for up-to-date information on the latest models, equipment, and prices.

American Communications Corporation
180 Roberts Street
East Hartford, CT 06108
Voice/TDD: 203-289-3491
Model(s): Amcom I, II; ring signaller.

Applied Communications Corporation
POB 555
Belmont, CA 94002
Voice: 415-592-1622
TDD: 415-592-1623
Model(s): TTY 42, 43, and modems

C-Phone, Inc.
553 Wolfner Drive
Fenton, MO 63026
Voice/TDD: 314-343-5883
Model(s): Mini-Phone; C-Phone-1A; Pocket-Phone II; and carrying case.

Krown Research, Inc.
6300 Arizona Circle
Los Angeles, CA 90045
Voice/TDD: 213-641-4306
Model(s): Porta Printer; Porta Printer Plus.

Novation, Inc.
18664 Oxnard Street
Tarzana, CA 91356
Voice: 800-423-5410
Model(s): N-Phone.

Plantronics
345 Encinal Street
Santa Cruz, CA 95060
Voice/TDD 408-426-5858
Model(s): VuPhone; VuPhone II; carrying case.

Phone-TTY, Inc.
1425 Plaza Road
Fair Lawn, NJ 07410
Voice: 201-796-5414
Model(s): TTYs, modems, and teleprinters.

Specialized Systems, Inc.
22449 Sorrento Valley Road
San Diego, CA 92121
Voice: 714-455-9000
TDD: 714-481-6060
Model(s): SSI System 100 Communicator (formerly PortaTel); SSI System 100 printer; SSI System 100 answerer; TeleSignaller; Rechargable battery pack; carrying case.

Ultratec, Inc.
POB 4062
Madison, WI 53711
Voice/TDD: 608-273-0707
Model(s): Superphone; various printers; battery pack.

A supplement to the TDD Factsheet, prepared by the National Information Center on Deafness, Gallaudet College, Washington, D.C. 20002. (Phone or TDD: 202-651-5109)

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PROJECT TIES

Apraxia

I. Definition

A. Apraxia is an articulatory disorder which impairs the programing of articulatory movements such as initiating, selecting and sequencing.

II. Characteristics

A. Failure to make appropriate vocal tract configuration or sounds.

B. Cannot arrive at desired configuration to make desired sound.

C. Able to make progressive approximations.

D. Inconsistency of attaining target.

E. Inability to structure articulators.

F. Rate of speech

1. Slow

G. Equal stress is given to all syllables

Dysphagia
(swallowing and feeding disorders)

I. Definition

A. Disorders in the process of feeding such as manipulating food in mouth, chewing, and/or swallowing.

II. Stages of development of oral motor control.

A. Reflexes
1. Gag
2. Laryngeal closure
3. Rooting
4. Suckle

B. 4-12 months
1. Decrease in reflexes.
2. Variability of motor patterns.
3. Decent of larynx
4. Sitting

C. 12-24 monti.
1. Cortical control over motor movements.
2. Phonological sophistication.

D. 24-36 months
1. Feeding and speech at voluntary levels.

III. Four phases of swallowing.

A. Oral preparatory

B. Oral (voluntary)

C. Pharyngeal phase
1. Swallowing reflex

D. Esophageal phase

IV. Swallowing disorders in neurologic populations.

A. Cerebral Palsy
1. Reduced tongue control. (Aspiration before swallow.)
2. Delayed reflex. (Aspiration before swallow.)

B. Myotonic Dystrophy
    1. Cricopharyngeal dysfunction. (Aspiration before swallow.)

C. Head trauma
    1. Delayed/absent reflex. (Aspiration before swallow.)
    2. Reduced tongue control.
    3. Cricopharyngeal dysfunction. (Aspiration after swallow.)
    4. Reduced pharyngeal peristalsis. (Aspiration after swallow.)
    5. Tracheoesophageal fistula. (Aspiration after swallow.)

Language Learning Disabilities

I. Definition

A. Learning disabilities is a generic term that refers to a heterogeneous group of disorders manifested by a significant difference in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual.

Even though a learning disability may occur concomitantly with other handicapping conditions, it is not the direct result of those conditions.
NATIONAL JOINT COMMITTEE ON LEARNING DISABILITIES

II. Characteristics associated with language learning disabilities.

A. Disruption in comprehension and/or production of language.

B. Word-finding problems.

C. Concrete approach to tasks.

D. Difficulty with story telling.

E. Reading/spelling difficulties.

F. Poor attending/very distractable

G. Difficulty organizing thoughts or sequencing information.

H. Socially immature

1. Breakdown in the ability to use abstract language such as inferencing and integrating language.

Dysarthria

I. Definition

   A. Disorder of neuromuscular control of the motor speech mechanisms such as respiration, phonation, resonation.

II. General Characteristics

   A. Weakness of the articulators.

   B. Paralysis of articulators.

   C. Incoordination of muscles used for speed.

   D. Abnormalities of tone.

III. Characteristics of Speech

   A. Imprecision of formulating consonants

   B. Distortion in the production of vowels.

   C. Repetition and prolongation of sounds.

   D. Inability to maintain proficiency of articulation.

   E. Irregular rate of speech.

McDonald, E.T., In G.C. Venderneider, E.K. Grilley (Eds) Non Vocal

Communication Techniques and Aids for the Severely Handicapped
Baltimore, MD - University Park Press

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DEFINITION OF COMMUNICATION AND ITS SIGNIFICANCE

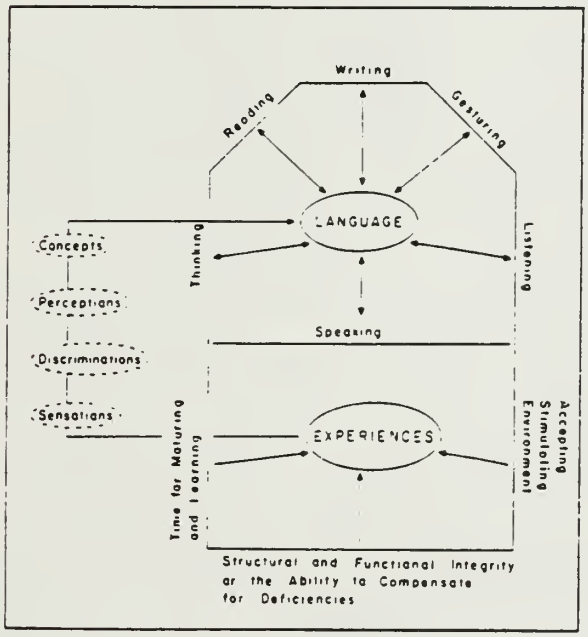
As we begin to consider different means of providing communication for the non-vocal child, it is important to discuss what we mean by "communication." A very important point for us to keep in mind is that communication cannot take place within just one person. There must be a listener or reactor. When developing communication aids for children we must also do something about the environment in which the child lives if communication is to take place. Communication is a function that takes place among persons who group themselves together to form a community. I want to emphasize the relationship of "communicate" to the concept of community . We suspect that many of the communication problems of several involved children stem from the fact that their community does not interact with them. Because they can't talk, non-vocal children often find themselves living in environments where people don't talk to them. Moreover, people tend to not interact with them socially in other ways as well. As a result non-vocal children, who are often non-ambulatory and unable to manipulate objects, have little opportunity to gain experience through interaction with others, thus seriously jeopardizing their development.

It would be impossible to exaggerate the significance of communication. It has been the cohesive force in human cultures. It is a vehicle for social interaction and it is essential for personal development. We have all seen older, physically involved children who appear to have very restricted personality development. They are often unmotivated we say. They are children who seem to be content to remain dependent upon others. They are children who don't seem to do as much as they are physically capable of doing. Perhaps they give us these impressions because they have not developed personally. One of the reasons for their restricted personal development is that they have not had the stimulation which comes from interaction in a communicative way with those persons around them. They have come to be, ans are content in being dependents in the community. Perhaps this is because they are not, and don't konw what it means to be, a member of their community.

FOUNDATIONS OF LANGUAGE DEVELOPMENT

I plan to represent some models on which we can hang some very elementary ideas about the development of language. We need this background in order to follow the arguments I will present for early identification of children at risk for failure to develop communication skills and for early intervention. We will be talking about the process which involves transferring information from one person to another person or persons. The first model depicts the 'foundations of language develop-

ment.' (Figure 1) We are suggesting that language, a component of communication, develops as a result of a child's interacting with its environment. For language to develop from these interactions, the child must have a sensorium which provides his nervous system with information about what is going on in the environment. The motor system, however, does not have to be intact for language to develop. We have seen many children who are severely handicapped motorically, but who give evidence of well developed receptive language and good manipulation of language in another modality. For language to develop the environment must provide appropriate stimulation for the child; and it must reinforce certain of the child's reactions so that these reactions will be likely to occur again. In other words the environment must provide language stimulation and must reinforce language behaviors if language for communication is to develop.



FOUNDATIONS OF LANGUAGE DEVELOPMENT

Figure 1.
Foundations of Language Development

Unfortunately, many severely involved children don't find this kind of environment. The mother does not get positive feedback from her efforts to communicate with the child. When she plays with him she does not get smiles or cooing. She does not hear the beginnings of vocal play, and consequently she does not get the kind of reinforcement she needs to continue this kind of stimulation. Also it may be that when the child attempts to respond, his behaviors are so bizarre or so abnormal that the mother gets negative feedback. She is pained and hurt by what she sees in her child when she attempts to communicate with him. Her natural reaction is to talk and play less with the child, and as a consequence the child has fewer opportunities to interact with his environment.

The interactions which take place during the timeof maturation and learning give rise to experience, the first of which are very simple. The child merely senses that something is occurring. It may be that he hears something or doesn't hear anything. He feels something, he doesn't feel anuthing. A little later he begins to notice that there are differences in these sensations and at that poirt he is discriminating between stimili. He later begins to develop perception by adding to these discriminative sensations some interpretation: mother's voice, father's voice, the og barking. A little later he will generalize his perception into con cepts - the building block of language.

Some Language Models

Language is employed in several ways which we will refer to as modalities for language use. Some ways of using language are receptive, some are expressive, and one is central. Perceptive uses of language would be listening and reading, with reading, of course, coming at a much later age. Expressive modalities would be speaking and gesturing, and the central modality would be thinking. It is possible to develop language without developing expressive skills. We have seen children who don't speak, and who are so severely physically handicapped they are capable of only the most elementary type of gesturing (eye movements or head nod) but who give evidence of a very rich receptive language development.

Speech is the most commonly employed modality for using language. Our model of speech production barely suggests the complexities of the speaking process. (Figure 2) In speech production three major proces-

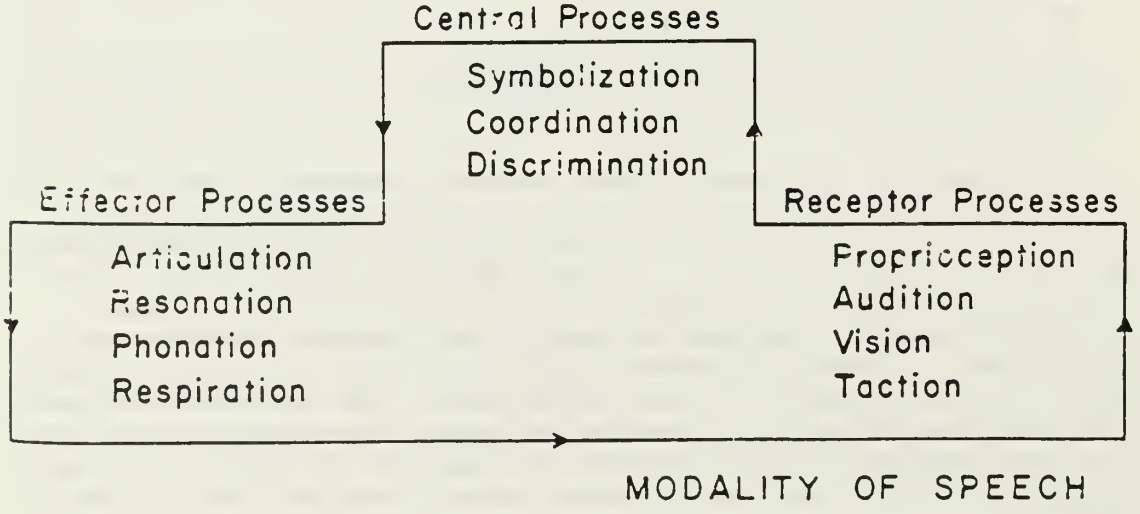


Figure 2. Modality of Speech

ses must be coordinated: receptor, central and effector. As receptors we have the auditory, proprioceptive and tactile senses. Vision may be helpful but is not nearly as important as these other senses for the development of speech. The central process could be organized in a number of different ways but basic to the relationship between speech and language is symbolizing function. It is in the central area that the input from the receptors is organized in such a way that it can be given some symbolic features and an appropriate motor command issued to the muscles of the speech producing mechanism.

Several effector processes are involved in speech production: respiration, phonation, articulation and resonation. In some cerebral palsy children breakdowns in these processes which probably indicate that the child is at risk can be detected at an early age.

In the widely used model of the source-filter theory of speech production (Figure 3) are counterparts of the effector portion of our model of speech production. The lungs represent respiration, the larynx represents phonation, and the supralaryngeal tract represents resonation and articulation. This model also corresponds to the effector component in Fairbanks control theory model of speech production. (Figure 4).

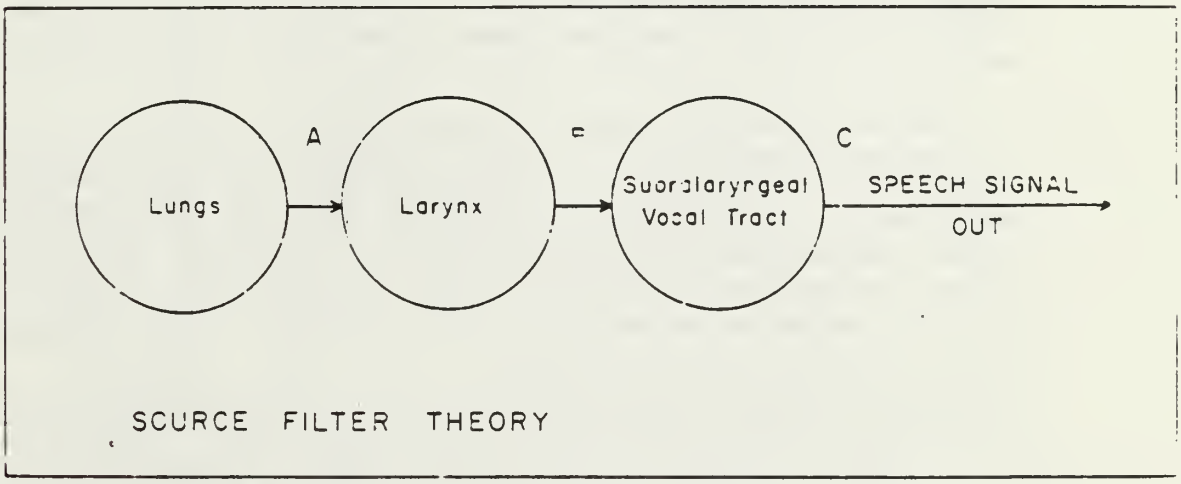


Figure 3. Source Filter Theory

In the Fairbank's model the input from the environment goes into a storage component. From storage a signal is directed to the effector unit which consists of a motor, generator, and modulator. To compare this model with the source-filter model envision a circle labeled 'lungs' drawn around the motor, a circle around the generator labled 'larynx," and a circle around the modulator labeled 'supralaryngeal vocal tract.' The two models indicate that air is directed from the lungs into the larynx and from the larynx into the supralaryngeal tract from which sounds are emitted. The acoustic output is sensed, heard and fed back into the comparator which, if there is an error signal,

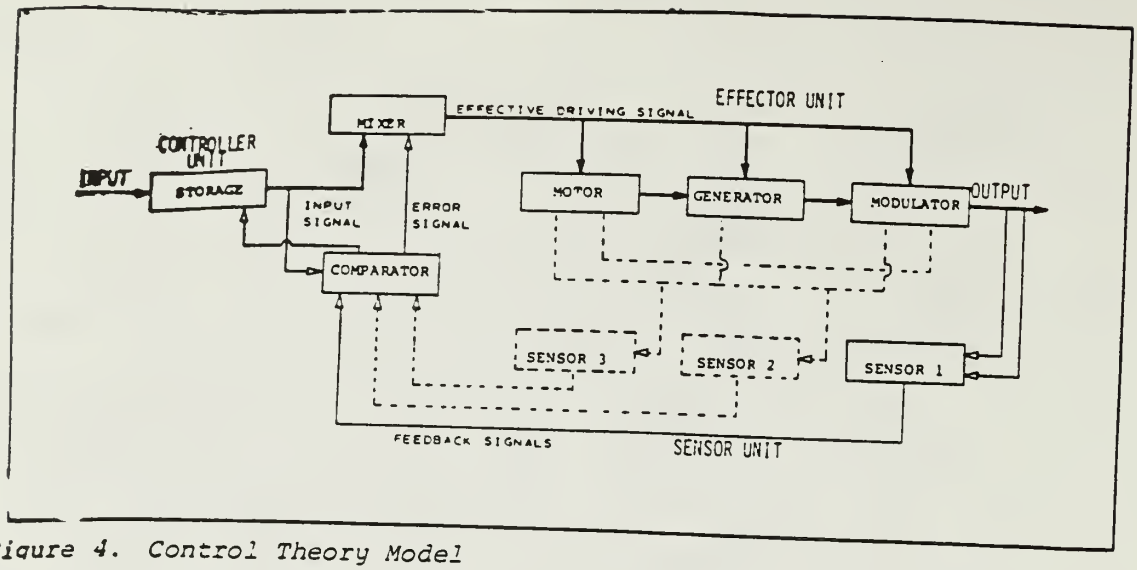


Figure 4. Control Theory Model

would report that some change is necessary. There is also sensory input into the comparator from the tactile and proprioceptive end organs, which come from the structures of the effector unit. This theory envisions a closed loop system: however, in the initial stage of speech learning it has to be an open loop. Only after the child has developed a program which gives him satisfactory match of output with what he has stored about input, does the system operate as a closed loop servosystem.

The storage component of the model might be expanded by adding a model of the memory system. (Figure 5) Envision these components of the memory system as included in the storage unit. An environmental input enters the sensory registers or sensory buffers on an ongoing basis as we are constantly being bombarded by visual, auditory, tactile and proprioceptive stimuli. Information doesn't remain in the sensory register very long unless we attend to it, thus removing it from the sensory buffer and transferring the information into a short term store. I want to stress this process because many cerebral palsied children are not good attenders: they have not developed attending skills. They may have sensory systems which work very well, but unless they can attend to sensations present in the sensory buffer they can not transfer information into short term store or long term store. Therefore, to teach this child to communicate you must be sure that he is attending to the stimuli you are presenting.

By attending, we get information into our short term store which is sometimes called the temporary working memory. Material doesn't stay in the store very long and there is a limit to how much the short term store can hold. It has been suggested that we can hold 7 plus or minus

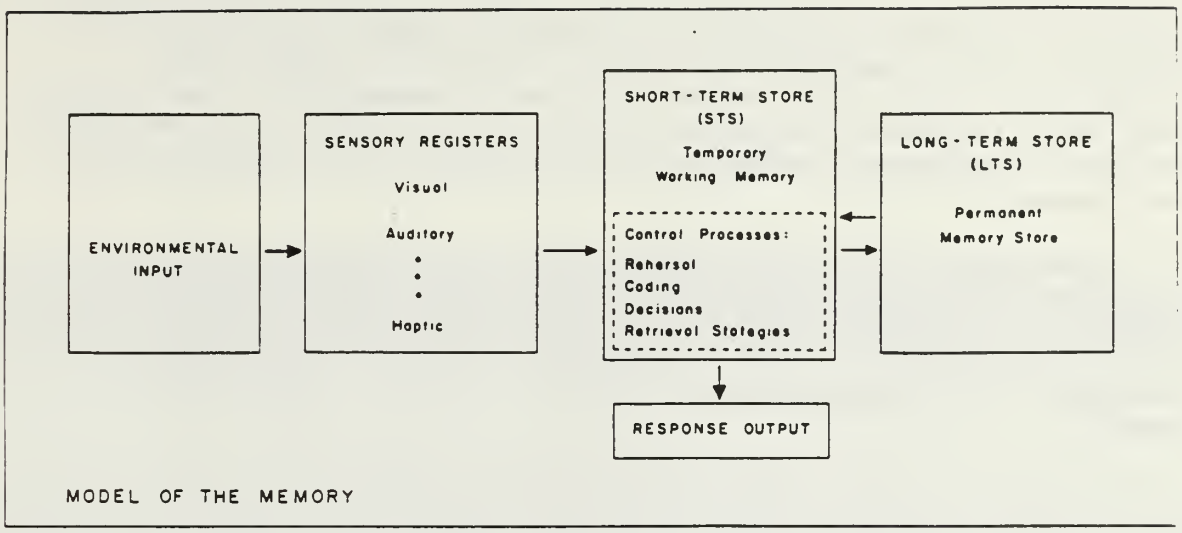


Figure 5. Memory Model

2 bits in this unit. Since material disappears from the short term store very quickly it is necessary to transfer it to long term storage if it is to be retained. To effect this transfer there are many procedures we can use. We can categorize, classify, encode, make decisions and develop retrieval strategies. It has been demonstrated that many children with learning problems have difficulties in this area because they haven't developed strategies for getting information from the short term store into the long term store: hence, the information disappears. When evaluating children, we should consider their memory function and, if they have difficulty here, find some ways to help them learn how to get material into their long term store. Once information is in long term memory it seems to be stored permanently. Scanning and other retrieval strategies however must be developed if the child is to make ready use of material in the long term memory.

Directing our attention again to the servosystem model (Figure 4) which we have elaborated by incorporating the memory system model, we can now take a look at the total speech process as defined by the model. First, there is an idea or message to be expressed which activates the central nervous system causing motor commands to be issued. These motor commands bring about patterns of contraction of respiratory, laryngeal, and articulatory muscles. The result of this muscle action is an acoustic signal. The acoustic signal will consist of a time series of formant patterns, transients, noise and so on. The output signal will consist of phonic symbols organized into words and sentences. The model includes a self-monitoring system. At the point where we have acoustic symbols as an output we can get auditory feedback. At the point in the model where there is muscle contraction and movement of structures there can be tactile and kinesthetic feedback. This kind of feedback loop has to be developed early. If it is not developed early, the child will experience difficulty in developing

self-monitoring skills. We see some children speak intelligibly when talking to their therapist but outside the situation where their helpers are, their speech becomes difficult to understand. One suspects that these youngesters are having difficulty monitoring their own speech and that their speech problem may stem from lack of an effective feedback system.

From these models it is apparent that there are many places where things might go wrong during the development of speech. For this reason it is important to identify, at a very early age, children who are having problems in order to help them to develop the specific skills necessary to develop communication and, if possible, fully functional speech.

NEURO-MUSCULO-SKELETAL SYSTEM

Objectives

After the workshop presentation, participants will:

1. Differentiate between various types of seizures.
2. Discuss the management and care of a child with a seizure disorder.
3. Discuss the management and care of a child with myelodysplasia.
4. List the danger signs of increased intercranial pressure.
5. Outline the treatment and care of a child with hydrocephalus.
6. List the characteristics, management and care of a child with osteogenesis imperfecta.

NERVOUS SYSTEM

ANATOMY

Central nervous system (CNS)

- organs: brain and spinal cord
- function: controls and coordinates body activities

Peripheral nervous system

- organs: motor, sensory and autonomic nerves
- function: sends and receives messages to and from the brain

DEFECTS IN BRAIN DEVELOPMENT

Anencephaly: absence of the cerebral hemispheres

Hydranencephaly: absence of the cerebral hemispheres with the space filled with fluid. The child is able to breathe because the brain stem is intact, but there is no voluntary motor or intellectual development

Agenesis of the Corpus Callosum: failure in the formation of the corpus callosum which connects the two cerebral hemispheres. This condition is also associated with other severe central nervous system malformations which may cause:

- seizures
- developmental delay
- hydrocephalus

Porencephalic Cyst: lateral ventricle becomes cyst-like and causes motor, sensory or visual defects, depending on the size and location of the cyst.

Encephalocele: a defect in the skull, usually at the back of the head, through which the brain, brain covering (meninges), or both extend. Unlike other brain defects, encephalocele can usually be repaired surgically. If this condition is accompanied by hydrocephalus, a shunt will be needed. If only the meninges protrude there is a 60% chance that the child will have normal intelligence and motor development.

Microcephaly: poor growth of the entire brain. A head circumference that is one or two standard deviations below the mean suggests abnormality. Causes for microcephaly include:

- genetic defect
- radiation or alcohol
- rubella
- anoxia at birth
- severe malnutrition

DISORDERS

Seizures: Seizures are characterized by abnormal, involuntary neuromuscular activity, accompanied by changes in consciousness or behavior, which results from damage to the central nervous system. Bursts of electrical impulses of different types or in different locations of the brain cause different kinds of seizures. Recurrent seizures are called epilepsy or recurrent convulsive disorder.

Idiopathic epilepsy: the term used when the cause is unknown. Although the cause of the majority of recurrent seizures cannot be definitely established, a specific defect in the metabolism of the brain is likely. Electroencephalographic (E.E.G.) tracings are abnormal in 90% of the cases.

(continued)

Organic epilepsy: associated with other genetic conditions. Convulsions may also occur after pre- or postnatal cerebral damage. These children frequently have a motor disability (such as cerebral palsy) and some degree of mental retardation.

Causes

- genetic defects
- damage to the brain from anoxia, hemorrhage or tumor
- fever
- infections
- metabolic disorders

Types of Seizures

Grand mal: accounts for 60% of all convulsive disorders. Prior to the seizure, the child may experience a very brief warning or aura, in the form of an unusual sensation. Two phases of the grand mal seizure are:

1) Tonic phase, during which there is usually a loss of consciousness, stiffening of the body, drooling, heavy breathing and incontinence
2) Clonic phase, is characterized by alternating rigidity and relaxation of the muscles

The tonic and clonic phases are usually followed by a period of drowsiness and disorientation, although some children may become extremely irritable.

(continued)

Petit mal: occurs most commonly in children between the ages of four and twelve. A large percentage (35 - 50%) of these children will also have grand mal seizures at some time in their lives.

Symptoms include:

- loss of consciousness without loss of muscle tone
- staring
- repetitive activity such as blinking or smacking lips
- lack of memory of the event

The episodes are brief, usually lasting from 5 to 30 seconds.

Simple febrile: occurs in 5 to 10% of children under the age of five and is precipitated by fever. This is a grand mal seizure lasting less than ten minutes. Unless the child has other types of seizures or abnormal neurological findings, he or she does not develop epilepsy.

Infantile spasms: begin at three to nine months of age and may occur hundreds of times a day. The head drops and the arms flex, giving the name "jacknife epilepsy" to this type of seizure activity. Infants who have this disorder do not have a good developmental prognosis. While the spasms may diminish, other types of seizures may replace them. Another name for this disorder is infantile myoclonic seizure.

Myoclonic/akinetic seizures: are characterized by brief, involuntary jerking movements of the extremities. The child loses muscle tone during an akinetic seizure. Both types are difficult to control and are often associated with a degenerative neurological process.

Management and care

During seizure:

1) stay calm

2) do not restrict the child's limbs

3) do not put anything into the child's mouth or force anything between his or her teeth

4) if possible, turn the child onto his or her side (so that saliva may flow from his or her mouth) and place a pillow under his or her head

Your primary task during a seizure is to prevent the child from being injured. After the seizure, he or she will need protection from the psychological effect of disorientation and the embarrassment caused by incontinence which may have occurred during the seizure. Most seizures are not treated as emergencies.

If, however, the child experiences a series of recurrent seizures or the seizure lasts as long as an hour (this may be individually determined for each child), he or she will need to be seen by a primary health provider. Blood levels of current medication are usually determined at that time.

Monitor seizure activity:

- record time, duration and type of seizure

Monitor administration of medication:

1) in order to give accurate dosage, do not mix medication with milk, juice or food

2) supervise an older child who is able to take his or her own medication; establish a schedule so that medication is not given during school hours, if possible

3) blood levels of medication need to be examined on a schedule. It is very important that these appointments are kept.

(continued)

Maintain meticulous oral hygiene: A generalized enlargement of the gums occurs in about 10 - 30% of children who receive Dilantin for seizure control. The gums are pale and firm and may hypertrophy to the point of covering the crowns of the teeth. Rubbing and brushing the gums will help avoid discomfort and improve the mealtime situation.

MYELODYSPLASIA: a birth defect in the developing lower spine and spinal cord. The defect and involvement range from minimal abnormality of the leg muscles, bowel and bladder function to complete paralysis of the lower extremities and severe impairment of bowel and bladder control. The ballooning out of the spinal cord and covering is called myelomeningocele.

Management and care

- initial counseling of parents who are faced with feelings of shock and grief
- surgical correction which is usually necessary soon after birth to close the defect and decrease the possibility of infection
- observation of head size and use of other methods (e.g., skull transillumination) to detect signs of intercranial pressure
- nutritional counseling to prevent obesity
- treatment of opthalmologic problems
- meticulous skin care, especially since the child may lack sensation in the lower limbs
- bowel training
    a. use of suppositories
    b. dietary control of constipation

(continued)

- catheterization
- performance of a shunting procedure for hydrocephalus
- developmental assessment
- physical therapy
- a coordinated approach to comprehensive care:

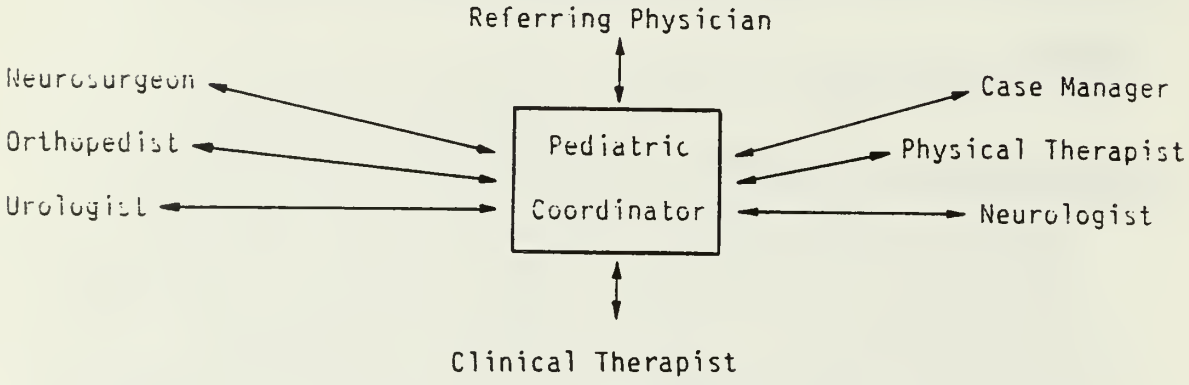


Figure 4.1 Interrelation of subspecialists in management of child with myelodysplasia

HYDROCEPHALUS

The term hydrocephalus, commonly referred to as "water on the brain," describes a condition in which fluid (hydra) builds up in volume inside the head (cephalus). The cerebrospinal fluid (CSF) which is constantly being produced, primarily in the lateral ventricles, (see Figure 4.2) has many important functions:

- it keeps brain tissue moist
- it carries away waste products from tissues in and around the brain
- it contains important chemicals and proteins

(continued)

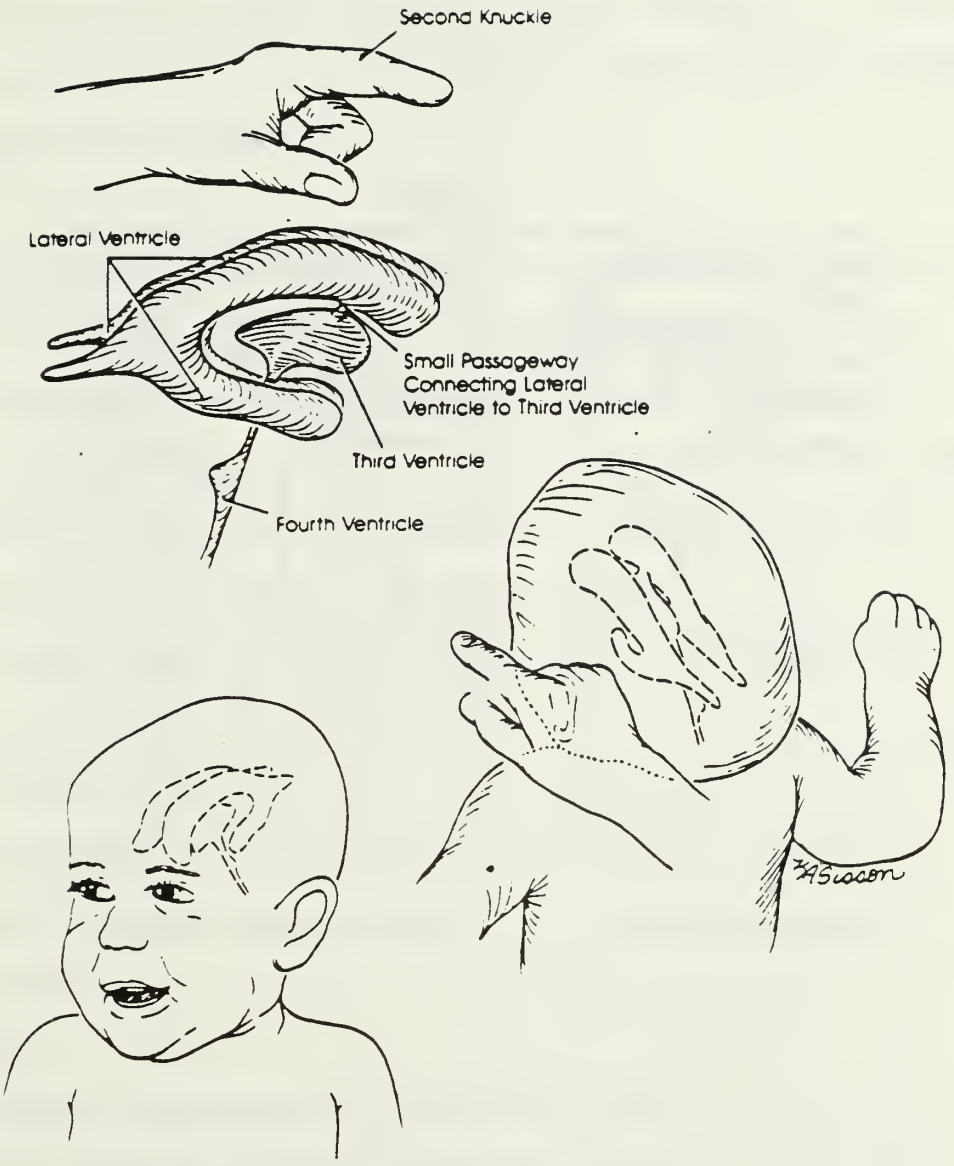


Figure 4.1 Ventricles of the Brain

SHUNTS

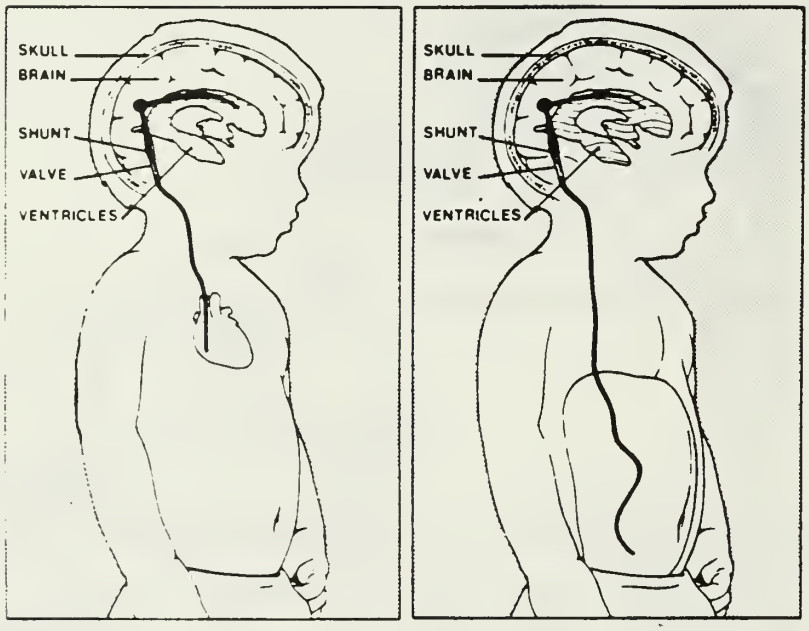


Fig. 4.2 Ventriculo-Atrial (VA) Shunt Ventriculo-Peritoneal (VP) Shunt

Small passageways, the third and fourth ventricles, lead to the surface of the brain at the base of the skull. The CSF flows through these ventricles downward around the spinal cord. Normally, the fluid is returned to the blood by special tissues which are connected to a large vein on the surface of the brain. Hydrocephalus is the result of blockage at some point in this pathway.

Causes

Congenital (present at birth): Lack of or improper development in the uterus. Examples of congenital hydrocephalus are aquaductal stenosis (narrowing of the passageway through the ventricles) and Dandy-Walker cysts. These cyst-like formations of the fourth ventricle occur when the openings from that ventricle to the base of the skull fail to develop properly.

Acquired hydrocephalus: results from conditions which damage the brain such as:

- meningitis
- hemorrhage
- head trauma
- brain tumor

Diagnosis

Sometimes hydrocephalus is obvious at birth:

- the child's head is much larger than normal
- the anterior fontanelle is bulging and tense
- the bones of the skull are more separated
- the child's eyes deviate downward

(continued)

Other signs include:

- vomiting
- seizures
- lethargy
- extreme irritability

Older children manifest different signs of increased pressure:

- loss of balance
- headaches
- gait disturbances
- irritability and changes in personality

Diagnostic tests

-. CT Scan

-. Angiogram

-. Pneumoencephalagram

Management and care

Shunting is the rerouting or bypassing of CSF away from the ventricular system, where it can be reabsorbed into the body. A small plastic tube is inserted into one of the lateral ventricles. In most cases it is passed under the skin into the peritoneum (abdominal cavity) where it is absorbed. In some cases, the shunt is passed through a large vein to the heart where the CSF is shunted back to the blood stream. The shunt contains a small one-way valve which controls the flow and maintains the CSF pressure inside the brain.

- Monitor for signs of intercranial pressure (see above), since the shunt is susceptible to failure for a variety of reasons
- Overcome the natural tendency to protect the child with a shunt, since they can be handled the same way as other children
- Consult a physician anytime the child is sick, so that he or she can rule out shunt malfunction.

(continued)

CEREBRAL PALSY (C.P.)

The most common nonprogressive neuromuscular handicapping condition of early childhood is cerebral palsy. Most (85%) of these children have developed this condition congenitally.

Characteristics of the child with C.P. will vary in degree and each child may be affected differently:

- insufficient head control
- inability to use one or both arms and hands to grasp and hold on to things; fisting of hands
- lack of balance and control posture, especially in sitting, standing and walking
- "scissoring" of legs
- extension, throwing head backwards

Causes

- Anoxia (lack of oxygen)
- Hemorrhage
- Infection
- Brain cyst
- Birth trauma
- Meningitis

Although at least 50% of children with C.P. are retarded, others have a wide range of mental capabilities. The only commonality among these children is the motor disorder present in the brain.

Associated disorders:

- feeding difficulty
- hearing and visual difficulties
- seizures
- speech problems
- learning disabilities

Types of C.P.

- Spasticity: stiffness of the muscles (hypertonia) occurs in about 60% of all cases

- Dyskinesia: fluctuating tone, with unwanted, involuntary movements describes 20% of all cases. Slow, writhing movements of the wrist and fingers (athetosis) may be accompanied by more abrupt jerky movements (choreoathetosis).

- Ataxia: balance difficulty occurs in about 1% of cases.

- Mixed: approximately 30% of children with C.P. have a combination of spasticity and dyskinesia or ataxia, with one type predominating

Management and care

A team approach involving specialists from several disciplines is needed:

- physical therapist works to facilitate motor development and to prevent or slow orthopedic problems

- occupational therapist helps caregivers in daily living activities, especially feeding techniques

- speech pathologist counsels on how to stimulate language development

- all therapists work together to help select the most appropriate equipment, such as special chairs and eating utensils to facilitate independence

- primary physician, orthopedist, opthalmologist and neurologist work together to treat and help prevent the usual childhood illnesses, prescribe braces, perform needed surgery, and control seizures.

Muscular System

ANATOMY

Organs and function

- organs: muscles, tendons and ligaments
- function: provide means for body movement and support

MUSCULAR DYSTROPHIES

Muscular dystrophies are of genetic origin in which gradual degeneration of muscle fibers occurs.

Classification is based on age of onset, the rate of progression of weakness, the distribution of muscle weakness and the mode of inheritance.

Childhood or Duchenne

- classic form occurs only in boys
- diagnosis rarely made before age of three, although history indicates a much earlier onset
- profound muscle atrophy (shrinking) occurs in late stages
- ambulation usually becomes impossible by age 12
- death occurs prior to age 20 in 75% of the cases

Management and care

- no effective treatment
- keep children active and in ambulatory state for as long as possible
- avoid very strenuous exercise in order to prevent further breakdown of muscle fibers
- surgery of heel cords may improve mobility
- genetic counseling is important

Secondary Conditions

Contractures and muscle weakness

When muscle groups develop asymmetrically and interfere with proper body alignment and range of motion of the joints, contractures occur. This condition is a symptom of a primary disability which limits the mobility of the child, thus further impeding development.

Management and care

- physical therapy to improve and help equalize muscle tone
- range of motion exercises to affected joints
- position change every 2 hours
- special attention to skin areas of affected parts

Motor disorders or degenerative neurological conditions often affect the peripheral nerves first. Conditions such as muscular dystrophy, multiple sclerosis, cerebral palsy are but a few which cause muscle weakness.

Skeletal System

ANATOMY

Organs and function

- organs: bones, joints and cartilage
- function: to support and protect other organs of the body

(continued)

DISORDERS

SKELETAL DEFECTS

- many are genetically determined
- some develop in utero, some after birth
- no therapy is effective for the majority of cases

Osteogenesis Imperfecta

- characterized by increased fragility of the bones, which are easily injured by slight or imperceptible trauma
- children usually have blue sclera (white of eye) and loose ligaments
- deafness may accompany disorder at birth or develop later
- intelligence may be normal, although development may lag because of lack of mobility and hearing impairment

Management and care

care of excess mucous by bulb syringe suctioning to control frequent upper respiratory infections

- maintain positioning as close to age level as possible to encourage developmental progress
- speech and hearing evaluations and therapy

BIBLIOGRAPHY

1. Bishop, Beverly. Spasticity: It's Physiology and Management. Physical Therapy, Volume 57, No. 4, 371 - 401, 1977.

2. Bobath, Berta. Abnormal Postural Reflex Activity Caused by Brain Lesions. London: William Heinemann Medical Books Limited, 1971.

3. Bobath, Berta and Bobath, Karel. Motor Development in the Different Types of Cerebral Palsy. London: William Heinemann Medical Books Limited, 1975.

4. Bobath, K. The Neuropathology of Cerebral Palsy and Its Importance in Treatment and Diagnosis. Cerebral Palsy Bulletin, Vol. 1, No. 8, 13- 33, 1959.

5. Delong, M. Central Patterning of Movement. In E. V. Evans et al. Central Control of Movement. Neurosciences Research Program Bulletin, 10- 30, 1971.

6. Downey, John A., and Darling, Robert C. Physiological Basis of Rehabilitative Medicine. Philadelphia: W.B. Saunders Co., 1971.

7. Fiorentino, M. Reflex Testing Methods for Evaluating CNS Development. Springfield, IL, Charles C. Thomas Publisher, 1963.

8. Gardner, Elizabeth B. and O'Connell, Alice L. Understanding the Scientific Basis of Human Movement. The Williams & Wilkins Co., Baltimore, 1972.

9. Gesell, A., Amatruda, C. Developmental Diagnosis. New York, Paul B. Hoeber Inc., 1949.

10. Hoskins, Theresa A., and Squires, Janet E. Developmental Assessment: A Test for Gross Motor and Reflex Development. Physical Therapy, Vol. 53, No. 2, 117 - 126, 1973.

11. Houk, J., Singer, Joshua and Henneman, Elwood. Adequate Stimulus for Tendon Organs with Observations on Mechanics of Ankle Joint. J. Neurophysiology, 34, 1051 - 1065, 1971.

12. Janson, Jan K. S. Spasticity - Functional Aspects. Acta. Neurol. Scandinav, Suppl. 3, Vol. 38, 41 - 51, 1962.

13. Kong, E. Early Treatment of the Motor Handicap. In Syllabus of Instructional Courses, Academy for Cerebral Palsy 26th Annual Meeting. 141 - 144, 1972.

14. Piaget, J. The Origin of Intelligence in Children. New York, International Univ. Press, 1952.

15. Prechtl, Heinz and Beintema, David. The Neurological Examination of the Full Term Newborn Infant. Little Club Clinics in Developmental Medicine No. 12, London: National Spastics Society, 1964.

16. Rood, M. Unpublished Notes from the Treatment of Neuromuscular Dysfunction Workshop: Rood Approach, Instructional Course, Mass. APTA, July 1976.

17. Saint-Anne Dargassies S. The Development of the Nervous System in the Foetus. Monograph available from the author, Central Neonatal de l'Association Claude Bernard, 123 Boulevard de Port-Royal, 75014, Paris, France; Switzerland, Nestle.

18. Salek, Barbro. A General Overview of Developmental Disabilities Part I: Philosophical Aspects of Assessment and Intervention From A Multidisciplinary Standpoint. In Developmental Disabilities Workshop, A Management Approach, Dept., Ex. Sci., Univ. of Mass., 3 - 9, 1975.

19. Taub, E. and Berman, A. J. Movement and Learning in the Absence of Sensory Feedback. In S. J. Freedman, The Neuropsychology of Spatially Oriented Behavior, Homewood IL, Dorsey Press, 173 - 191, 1968.

20. Tokizane, Toshihiko, Murao, Makoto, Ogata, Tamotsu, and Kondo, Tatsuko. Electromyographic Studies on Tonic Neck, Lumbar, and Labyrinthine Reflexes in Normal Persons. Jap. J. Physiol., Vol. 2, 130 - 146, 1951.

21. Weisz, Stephen. Studies in Equilibrium Reaction. J. Nerv. Ment. Dis., Vol. 88, 150 - 162, 1938.

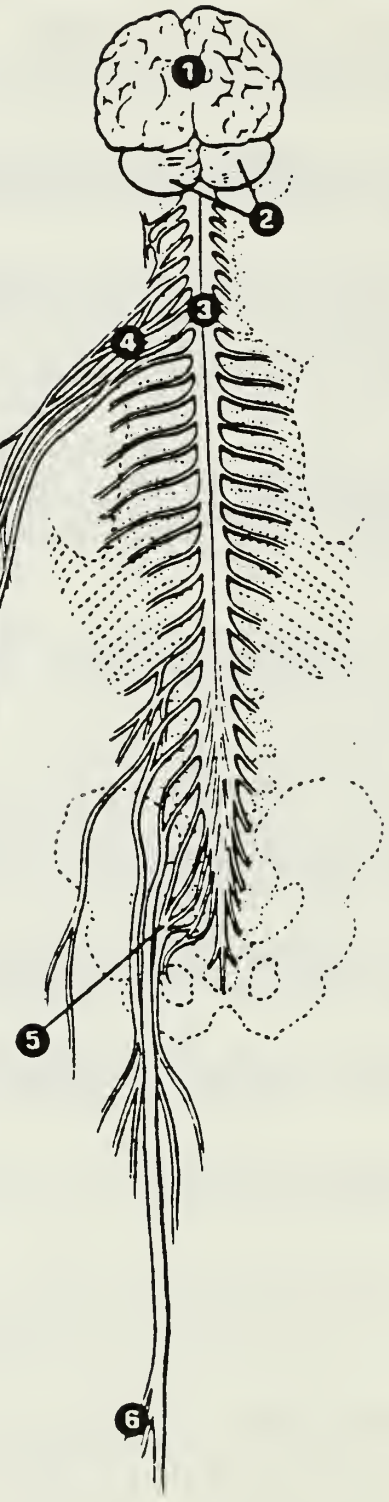
22. Wilder, J. Basimetric Approach (Law of Initial Value) To Biological Rhythms. Annals N. Y. Acad. Sci., Vol. 98, Art. 4, 1211 - 1220, 1962.

Fig. 1

Central Nervous System

Messages to and from the brain travel along the spinal cord and nerves seen branching off the cord.

1 Cerebrum
2 Cerebellum
3 Spinal cord
4 Brachial plexus
5 Sacral plexus
6 Peripheral nerve



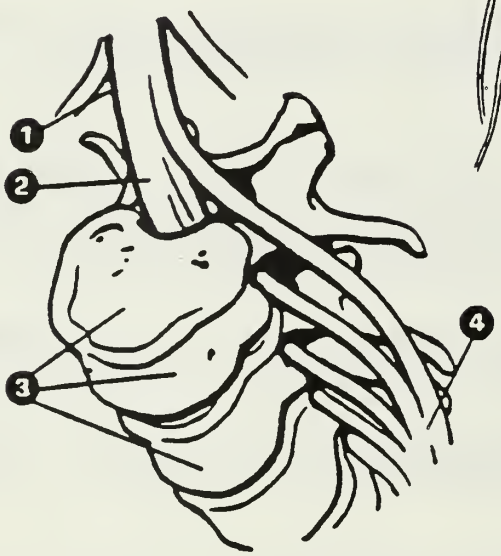


Fig. 2

Section of Vertebral Column

Upper vertebrae have been removed to show location of the spinal cord within the canal.

1 Meninges
2 Spinal cord
3 Vertebrae
4 Nerves branching off cord

From Medical Aspects of Developmental Disabilities in Children Birth to Three, Edited by James Blackman, M.D., The University of Iowa, 1983.

Neuroanatomy

James A. Blackman, M.D.

The Nervous System

THE CENTRAL NERVOUS SYSTEM (CNS)

BRAIN—Includes the cerebrum, cerebellum, midbrain, pons, and medulla oblongata.

SPINAL CORD—Divided into cervical (neck), thoracic (chest), lumbar (lower back), and sacral (lowest back) sections

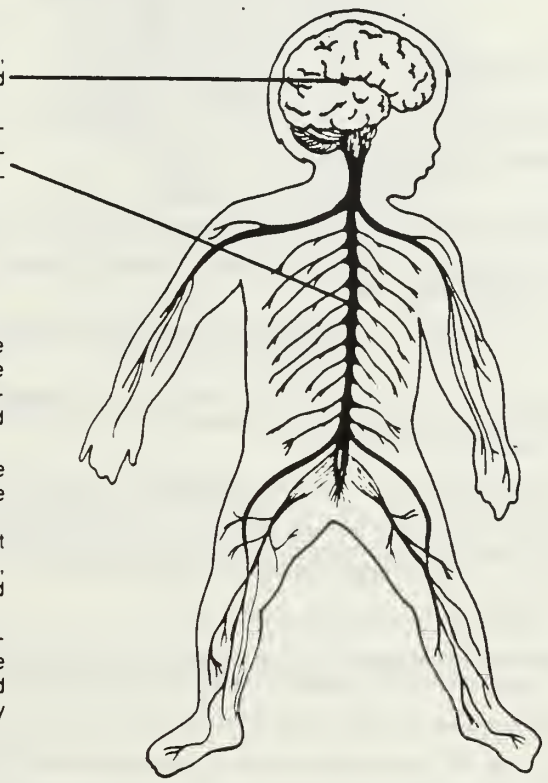
THE PERIPHERAL NERVOUS SYSTEM (PNS)

These nerves connect with the brain or spinal cord but originate or terminate outside these structures in areas such as the skin and muscle

MOTOR NERVES—Innervate the skeletal muscles, such as the biceps of the arm.

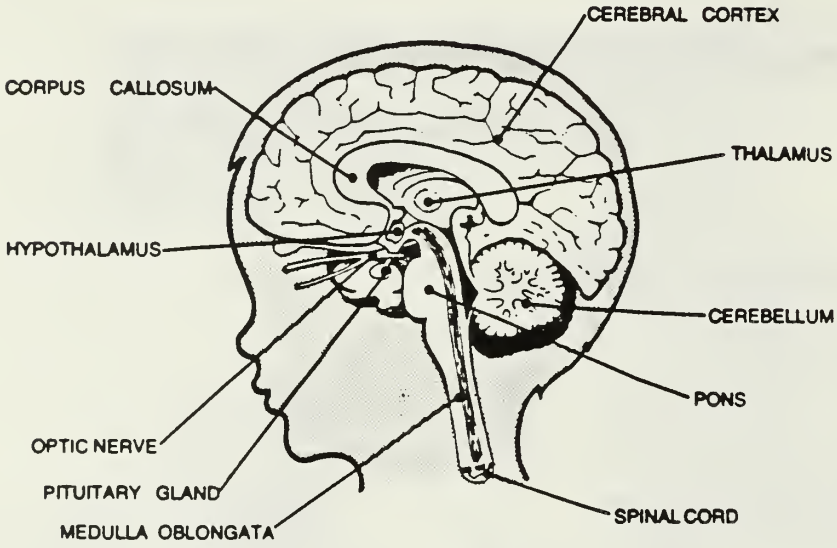
SENSORY NERVES—Transmit impulses from receptors for pain, taste, muscle tension, touch, and other stimuli.

AUTONOMIC NERVES—Innervate cardiac muscle, glands, the muscles of the intestines, and other organs not under voluntary control.



The Central and Peripheral Nervous Systems

Important Structures of the Brain and Their Functions



CEREBELLUM—The part of the brain responsible for muscle synergy and coordination

CEREBRAL CORTEX—The surface gray matter of the brain, generally considered responsible for "thinking" and volitional activity

CORPUS CALLOSUM—Joins the cerebral hemispheres, allowing them to "communicate" with each other

HYPOTHALAMUS—Regulates the autonomic nervous system, causing sweating, changes in heart rate, and intestinal contractions, also regulates appetite, body temperature, and the physical expressions of emotion (e g , flushing of the skin)

MEDULLA OBLONGATA—Nerve fibers from higher brain centers pass through here on their way to the spinal cord The hearing and balance nerves enter the brain here Certain nerves which control and receive information from the mouth, throat, neck, heart, and abdominal viscera leave and enter here Also, nerve fibers from the motor strip of each cerebral hemisphere cross over here to control movement on the opposite side of the body

OPTIC NERVE—The route traveled by visual impulses

PITUITARY GLAND—Releases hormones regulating water balance in the body, ovulation, growth, thyroid gland function, and the release of other hormones by the adrenal gland

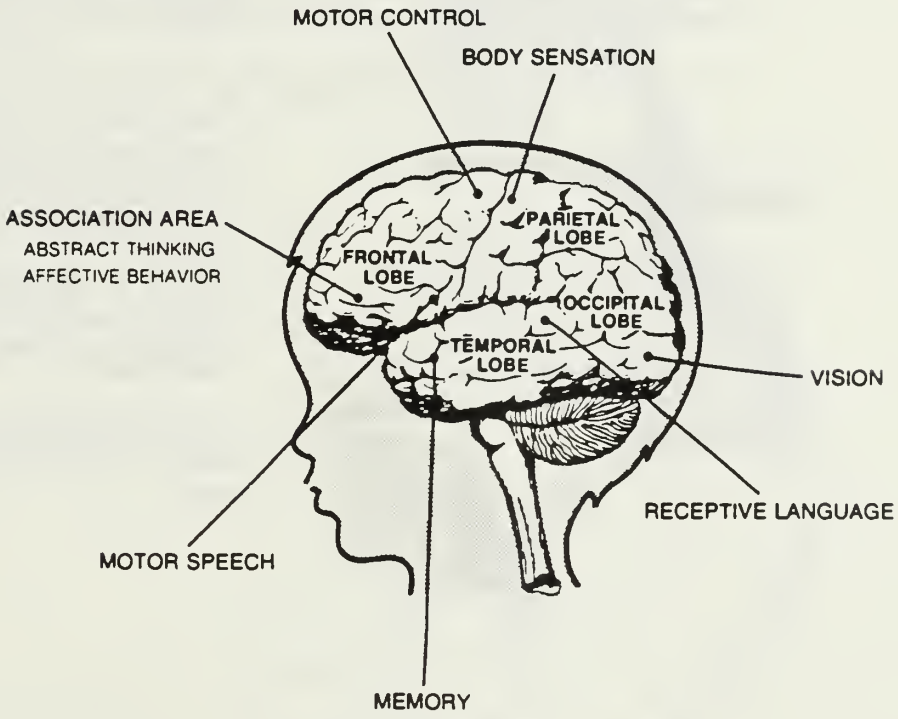
PONS—Nerves to and from the face originate and terminate here

SPINAL CORD—Conduit for motor and sensory fibers going to and from the brain

THALAMUS—The switching station for impulses going to the cerebral cortex

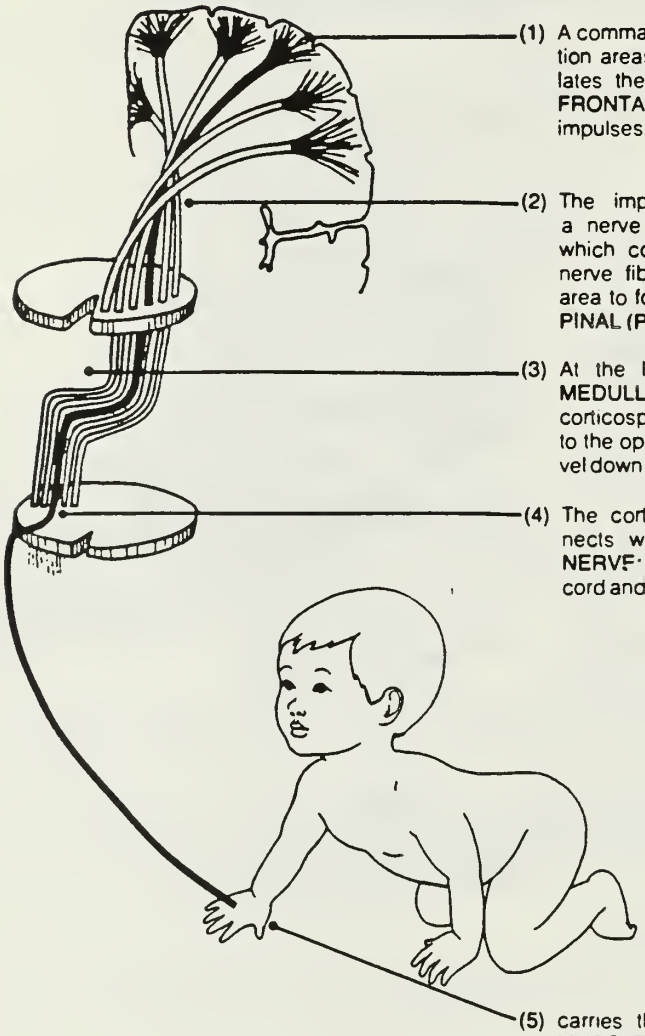
Midline Section of the Brain

Areas of Specialized Function



Topography of the Cerebral Cortex

Control of Voluntary Movement



(1) A command from the association areas of the brain stimulates the motor area of the **FRONTAL LOBE**, triggering impulses.

(2) The impulses travel down a nerve "tract," or bundle, which converges with other nerve fibers from the motor area to form the **CORTICOSPINAL (PYRAMIDAL) TRACT.**

(3) At the lowest level of the **MEDULLA**, the fibers of the corticospinal tract cross over to the opposite side, then travel down the spinal cord.

(4) The corticospinal tract connects with a **PERIPHERAL NERVE** which leaves the spinal cord and

(5) carries the impulses to the **MUSCLE**, causing it to contract and make the desired movement.

Control of Voluntary Movement

Refinement and coordination of movement is dependent on input from several other important structures outside the pyramidal system. The basal ganglia modulate pyramidal tract activity, and the cerebellum coordinates muscles so that they perform smoothly and accurately. The vestibular system of the inner ear helps the body maintain equilibrium; and special sensory organs in the skin, eyes, muscles, tendons, and joints provide the brain with continuous feedback regarding the position and movement of the limbs.

Damage in any of these areas can interfere with the execution of voluntary movement:

Damaged area	Result of damage
• Corticospinal tract or motor areas of the cerebral cortex	• Spasticity with some paralysis
• Basal ganglia	• Movement disorders
• Cerebellum	• Problems with balance and coordination (ataxia)
• Peripheral nerve and muscle	• Weakness or flaccidity

Febrile Seizures

A Consensus Development Conference on Febrile Seizures was held at the National Institutes of Health on May 19-21, 1980. The purpose of the conference was to bring together practicing physicians, research scientists, consumers, and others in an effort to reach general agreement on the risks of sequelae in children with febrile seizures and to compare them with the potential risks and benefits of prophylaxis with anticonvulsants.

On the first 2 days of the meeting, a consensus development panel and members of the audience reacted to evidence presented on the following questions:

- What is a febrile seizure?
- What are the risks facing the child who has a febrile seizure?
- What can chronic or intermittent prophylaxis accomplish in reducing those risks?
- What are the potential risks of prophylaxis, using the available forms of therapy?
- What is a rational approach to management of children with febrile seizures? Which children should be considered for prophylaxis?
- Are further clinical, experimental, or epidemiologic studies necessary?

National Institutes of Health
Consensus Development
Conference Summary
Volume 3 Number 2

The members of the consensus development panel represent the disciplines involved with treating and evaluating management of children with febrile seizures. The physicians were nominated for their role on the panel by four specialty medical associations: the American Academy of Pediatrics, the American Academy of Neurology, the American Academy of Family Physicians, and the Child Neurology Society. The panel met following the formal presentations and discussions to examine and debate the issues, based on the evidence presented. This summary is the result of these deliberations.

The National Institutes of Health urges that this summary statement be posted, duplicated, and distributed to interested staff.

1. What is a febrile seizure?

A febrile seizure[1] is an event in infancy or childhood, usually occurring between 3 months and 5 years of age, associated with fever but without evidence of intracranial infection or defined cause. Seizures with fever in children who have suffered a previous nonfebrile seizure are excluded. Febrile seizures are to be distinguished from epilepsy, which is characterized by recurrent nonfebrile seizues.

2. What are the risks facing the child who has a febrile seizure?

Children who suffer a febrile seizure generally enjoy normal health after the episode. They are, however, at some risk in several respects. Thirty to 40 percent of children who have one febrile seizure and who do not receive prophylactic therapy will experience a second. The seizure itself is frightening and frequently may be emo-

[1] A cerebral seizure is an abnormal, sudden, excessive electrical discharge of neurons (gray matter) which propagates down the neuronal processes (white matter) to affect an end organ in a clinically measurable fashion.

tionally disburbing to the family. During a seizure, there is, additionally, a minimal chance of physical injury. The occurrence of a second or subsequent febrile seizure does not, in itself, greatly change the risk of epilepsy.

A small percentage of children who have had a febrile seizure may have nonfebrile seizures, that is, epilepsy. Significant risk factors separate children at high risk of developing nonfebrile seizures from those at low risk. The high risk group, for which one study showed a 13 percent incidence of epilepsy, is characterized by the presence of at least two of the following risk factors:

- a family history of nonfebrile seizures
- abnormal neurological or developmental status prior to febrile seizure
- an atypical febrile seizure, such as a prolonged or focal seizure.

Only 2 to 3 percent of children who have none or one of the above risk factors subsequently develop nonfebrile seizures. The child with febrile seizures may have a neurological deficit, such as mental retardation, motor deficit, and sensory and perceptual abnormalities. It is generally believed that when present, these central nervous system (CNS) deficits have usually antedated the febrile seizures. There is no convincing experimental or epidemiological evidence that these deficits reflect neurological injury occurring at the time of the febrile seizure.

3.
What can chronic or intermittent prophylaxis accomplish in reducing those risks?

The only risk demonstrated to be affected by therapy is that of recurrence of a febrile seizure. Numerous studies show that the risk of recurrence of febrile seizures can be reduced by the continuous daily administration of phenobarbital at appropriate dosage to achieve minimum therapeutic blood levels (about 15 mcg/ml). Preliminary evidence suggests that the frequency of febrile seizures may also be reduced by the prompt administration of diazepam by rectum, or possibly other agents, at the onset of acute febrile illness. There is no evidence to suggest that phenytoin is effective in prophylaxis of febrile seizures.

Maintenance Therapy. While prolonged administration of phenobarbital is an accepted method of reduction of the frequency of febrile seizures, the long-term effects of such management are still poorly understood and require further investigation. Valproic acid has been reported to be effective; however, hepatic toxicity following the prolonged use of valproic acid has been reported. Thus, when this drug is used, liver function should be closely monitored.

Intermittent Therapy During Febrile Episodes. Intermittent use of phenobarbital administered orally at the usual recommended dosage (3-5 mg/kg) has been shown to be ineffective in promoting therapeutic blood levels. Diazepam, when administered as suppositories,[2] apparently is absorbed rapidly enough to provide immediate protection from subsequent seizures in a high percentage of febrile children.

There is no evidence to support the concept that prolonged therapy with anticonvulsants prevents the development of epilepsy or significant neurological deficits.

4.
What are the potential risks of prophylaxis, using the available forms of therapy?

The potential risks of continuous prophylaxis are those predictable side effects, toxic manifestations, or idiosyncratic reactions that may be peculiar to the anticonvulsant drug selected for therapy.

Drugs currently administered on a long-term basis to prevent febrile seizures are phenobarbital, diazepam, and valproic acid and, to a lesser extent, phenytoin and carbamazepine. Phenobarbital is by far the most commonly used agent.

Side effects and toxic reactions are reported in up to 40 percent of infants of children receiving phenobarbital. These reactions are usually of the following types:

1. Behavioral changes—hyperactivity to extreme irritability and, rarely, somnolence.

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[2]Not yet available in the United States.

VII. Continuation of animal experiments to clarify the effects of single recurrent seizures on brain maturation and development, utilizing both experimental animal models and kindling techniques.

The conference was sponsored by the National Institute of Neurological and Communicative Disorders and Stroke, in cooperation with the National Institute of Child Health and Human Development and with the assistance of the Office for Medical Applications of Research, NIH.

Members of the Consensus Development Panel were:

Edwin L. Kendig, Jr., M.D. (Chairperson), Professor of Pediatrics, Virginia Commonwealth University, Medical College of Virginia, Richmond, Virginia

Paul R. Dyken, M.D., Professor and Chief, Pediatric Neurology, Medical College of Georgia, Augusta, Georgia

Nyrma Hernandez, Deputy Executive Director for Program Services, Epilepsy Foundation of America, Washington, D.C.

Marion C. McKee, M.D., F.A.A.P., Clinical Professor of Pediatrics, University of Vermont, Director of Child Development Clinic, Vermont State Health Department, Burlington, Vermont

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Elbert E. Smith, M.D., Pediatrician, Kansas City, Missouri

B. J. Wilder, M.D., Professor of Neurology and Neuroscience, University of Florida College of Medicine, Chief, Neurology Service, Veterans' Administration Medical Center, Gainesville, Florida

Janet Wittes, Ph.D., Associate Professor, Department of Mathematical Sciences, Hunter College of the City University of New York, New York, New York.

From Medical Aspects of Developmental Disabilities in Children Birth to Three, Edited by James Blackman, M.D., The University of Iowa, 1983.

ANTICONVULSANT MEDICATIONS AND THEIR SIDE EFFECTS

Name	Type of seizures treated	Side effects/ adverse reactions
Carbamazepine (Tegretol)	Grand mal Focal Psychomotor	Vomiting, headache, drowsiness, blood dyscrasia, ataxia
Clonazepam (Clonopin)	Petit mal Myoclonic (Minor motor)	Hyperactivity, short attention span, impulsive behavior, drowsiness, ataxia, vertigo or dizziness, confusion, excessive weight gain, drooling
Corticosteroids ACTH	Infantile myoclonic	Moon face, elevated blood sugar, susceptibility to infections, thinning of the bones, muscle weakness
Diphenylhydantoin (Dilantin)	Grand mal Psychomotor Focal	Gingival hyperplasia, hirsutism, dermatitis rash (in approximately 5-10 percent of patients; drug should be discontinued), drowsiness, gastric distress, nystagmus, ataxia, dysarthria, blood dyscrasias
Ethosuximide (Zarontin)	Petit mal	Dizziness, GI distress: nausea, vomiting, anorexia, leukopenia, kidney dysfunction
Phenobarbital (Luminal)	Grand mal	Rash (Stevens-Johnson syndrome), ataxia, hyperactivity, questionable effect on cognitive performance, blood dyscrasias
Primidone (Mysoline)	Grand mal Psychomotor	Drowsiness, dizziness, abnormal behavior, ataxia, rash, blood dyscrasias, diplopia, nystagmus
Valproic acid (Depakene)	Petit mal Grand mal Mixed myoclonic-akinetic	Nausea, vomiting, drowsiness, incoordination, dizziness, skin rash, liver toxicity, hair loss, weight gain

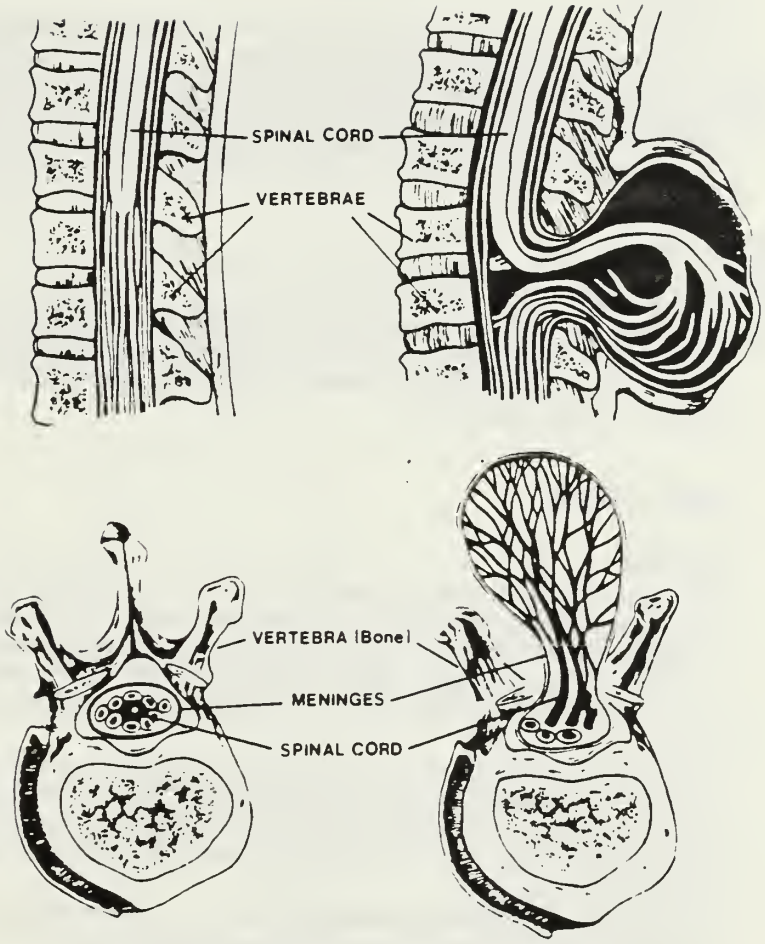
Myelomeningocele

Mark L. Wolraich, M.D.

DESCRIPTION

Myelomeningocele, also known as meningomyelocele and spina bifida, is a midline defect of the skin, spinal column, and spinal cord.

During the latter part of the first month of pregnancy, when the child is developing in the uterus, the spinal cord (myelo-) and vertebrae around it do not form properly. In the normal child, the spinal cord forms into a straight column, covered first by membranes (meningo-) and then by a bony spine. In the child with myelomeningocele, the membranes pouch out at some point along the back. As the spinal cord develops, it does not follow a straight column but pushes out instead into the membranous sac (-cele), where it does not form in the normal way. Some or all of the nerves coming out of the spine below the sac are not hooked up properly to the spinal cord and thus to the brain.



Normal Spine Myelomeningocele

There are two other types of open spine defect: meningocele and spina bifida occulta. With meningocele, the spinal cord itself does not pouch out, only the membranes surrounding it. With spina bifida occulta, the back of the vertebrae fail to form, but there are no abnormalities in the membranes, spinal cord, or skin.

Children with myelomeningocele may be characterized by hydrocephalus, mental retardation, and, depending upon the location of the defect along the spinal column, lack of control of leg muscles, lack of bladder and bowel control, lack of sensation in the skin, and/or curvature of the spine (scoliosis).

CAUSE

The exact cause of myelomeningocele is not known; it may, in fact, result from a combination of causes. There is no proven link between this condition and any medication, infection, or environmental condition. Nor are parents carriers of a gene that specifically causes myelomeningocele, though they may carry genes which make them susceptible to various nongenetic (e.g., environmental) factors known to be associated with it.

INCIDENCE

Myelomeningocele is one of the most common developmental defects of the nervous system; the incidence is about one in every thousand births. The chance of having a second child with this condition is somewhere between 1 in 20 and 1 in 40.

DETECTION

Prenatal

Myelomeningocele may be detected in the fetus through amniocentesis—by measuring the amount of alpha fetal protein (AFP) and acetylcholinesterase in the amniotic fluid. These proteins are found in high concentration in spinal fluid, which, in the child with myelomeningocele, leaks through the membrane and into the amniotic fluid surrounding the fetus.

Another, easier method of testing for myelomeningocele in the fetus is measuring the amount of alpha fetal protein in the mother's blood. This test, which must be done between the twelfth and fourteenth weeks of gestation, is not as accurate as amniocentesis, for which it is sometimes used as a preliminary.

Sometimes sound waves bounced off the fetus (ultrasonography) make the defect visible. This procedure is not always reliable, however.

Postnatal

Initial diagnosis is not difficult because the spinal lesion is present at birth and easily observed. The extent of the problem can be determined by assessing the lesion itself as well as the muscle groups affected. In rare cases, the defect is covered by skin and goes undetected in the newborn period.

COURSE

Myelomeningocele is a static condition; that is, there is no progression of the defect. However, secondary problems (urinary, for example) can worsen and require intensive management.

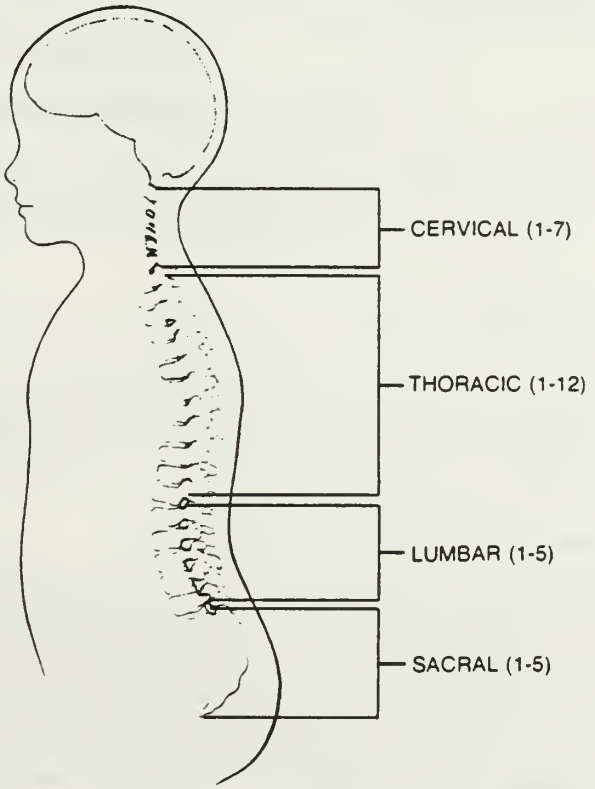
ACCOMPANYING HEALTH PROBLEMS

Hydrocephalus

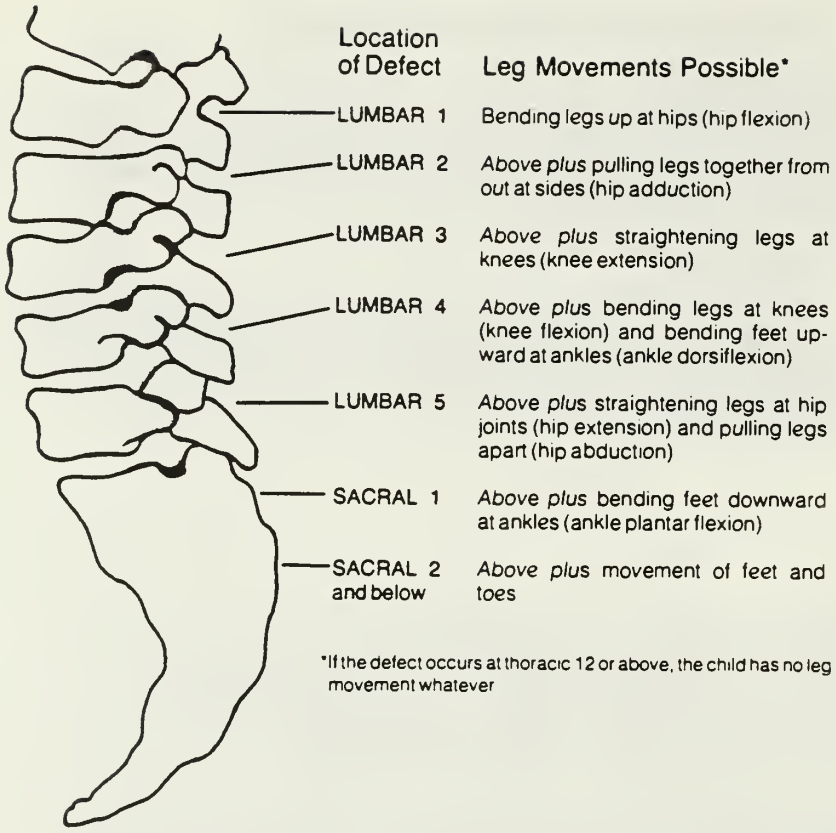
In about 80 percent of children with myelomeningocele, the spinal fluid is prevented from leaving the brain and being absorbed into the blood stream. The resultant increase in pressure may cause brain damage and, hence, mental retardation.

Muscle control

Because the nerves to the lower part of the body are not properly connected to the spinal cord and brain, there may be little or no control of leg muscles. The higher up the defect is on the spinal cord, the greater the paralysis. Most myelomeningocele defects occur in the thoracic, lumbar, or sacral regions of the spine:



Regions of the Spine


Location of Defect
Leg Movements Possible*
LUMBAR 1
Bending legs up at hips (hip flexion)
LUMBAR 2
Above plus pulling legs together from out at sides (hip adduction)
LUMBAR 3
Above plus straightening legs at knees (knee extension)
LUMBAR 4
Above plus bending legs at knees (knee flexion) and bending feet upward at ankles (ankle dorsiflexion)
LUMBAR 5
Above plus straightening legs at hip joints (hip extension) and pulling legs apart (hip abduction)
SACRAL 1
Above plus bending feet downward at ankles (ankle plantar flexion)
SACRAL 2 and below
Above plus movement of feet and toes
*If the defect occurs at thoracic 12 or above, the child has no leg movement whatever

Relationship Between Level of Defect and Leg Movement—*Incomplete lesions account for variations among children with myelomeningocele.*

Problems with bladder and bowel control

Because the nerves involved in bladder control come from the lower part of the spinal cord (the second, third, and fourth sacral segments), most children with myelomeningocele have neurogenic bladders. This means they may not feel the urge to urinate or have control of the urinary sphincter. A neurogenic bladder, if not cared for properly, may cause damage to the kidneys, either because the urine cannot get out properly (causing pressure on the kidneys) or because not all the urine is emptied from the bladder (causing infections). Treatments are available to prevent urinary tract infection and subsequent kidney damage.

The nerves involved in bowel control also come from the lower part of the spinal cord, and children with myelomeningocele frequently have neurogenic bowels. This may result in constipation and bowel movement accidents (incontinence).

Curvature of the spine (scoliosis)

Due to poor muscle control and the structural defect of the spine, straight alignment is sometimes not maintained. This can lead to a fixed tilt of the pelvis and curvature of the spine, causing poor sitting balance and excessive pressure on certain areas of the skin.

Problems with psychosocial development

Both the nature of the defect and the functional difficulties which accompany it may place strains on parent-child relationships. As the child grows older, functional limitations may lead to psychological and social maladjustment.

Pressure sores (decubitus ulcers)

Many children with myelomeningocele lack sensation in their lower extremities, making them prone to pressure sores. The skin should be checked frequently for reddened areas—the first sign of a problem.

MEDICAL MANAGEMENT

The complexity of the dysfunction and the number of organ systems involved demand the participation of many surgical and medical specialists and health-related personnel. An interdisciplinary team is frequently necessary to provide appropriate coordinated care.

Spinal lesion

To prevent germs from entering the open defect and causing serious infections in the spinal cord and brain, the lesion is generally repaired surgically within the first 24 to 48 hours of life.

Hydrocephalus

To prevent damage to brain tissue, the increased intracranial pressure is treated with a shunt, which is surgically placed, usually within the first two months of life.

Urinary tract

Urologic management begins at birth. In the past, various surgical procedures were used to redirect urinary flow and preserve kidney function. But conservative therapies now appear to be effective. These include periodic assessment of urinary tract function and intermittent catheterization to help prevent both urinary tract infections and "accidents."

Orthopedics

Evaluation begins at birth. The aims of management procedures are to preserve normal joint structures, to release contractures, to correct deformities, and to facilitate weight bearing and, where possible, ambulation. (Many of these children can learn to walk with the aid of braces and crutches.)

Psychosocial problems

Support for both child and family must begin with the child's birth and continue throughout his lifetime.

IMPLICATIONS FOR EDUCATION

The constant occurrence of acute problems—such as shunt malfunction, urinary tract infection, and repeated hospitalizations and surgery—combines with the socially limiting nature of such problems to affect almost every aspect of the child's performance in an educational setting.

Myelomeningocele generally has no effect on a child's stamina, although the accompanying hydrocephalus may cause attention disorders, learning disorders, and even mental retardation. Educational assessments are necessary to determine what types of learning problems—if any—a child may have.

Because of the damaged nerves along the spine, children with myelomeningocele may not experience the amount of weight bearing necessary for bone development and strengthening; they are therefore more prone to fractures in the lower extremities. Too, they may lack sensation in certain areas of the skin, increasing considerably the risk of burns, abrasions, and pressure ulcers. They may also lack bladder or bowel control and be participating in special bladder and bowel regimes at school. Because these children are less active than normal children, they are prone to obesity and may be following certain nutrition recommendations. Too, the excess weight can impede ambulation and contribute to the development of pressure sores.

The extent of physical and mental problems varies with the location of the defect; some children with myelomeningocele have relatively few of the problems listed here.

HOME CARE INSTRUCTIONS - CREDE METHOD OR MANEUVER

This method is used to remove urine from the bladder by applying hand pressure. This is done to keep the bladder empty so that urine will not be stored in the bladder for long periods, causing infections.

Hand pressure is applied by using the flat part of your four fingers. Beginning at the umbilicus (navel), apply firm and gentle pressure downward towards the pubic bone and genital area. (A slow, gentle circular massage may increase the effectiveness of emptying the bladder for some children.) This pressure should be applied 4 to 6 times every 2, 3 or 4 hours, as directed by the doctor. You should Crede your child's bladder regularly and faithfully every day -- it is a very important part of your child's care.

Your child may cry and tighten his stomach muscles: try to get him to relax, or press as the child takes a breath. As he becomes used to this, it will be easier, and as your child becomes older he will be able to learn to do it himself.

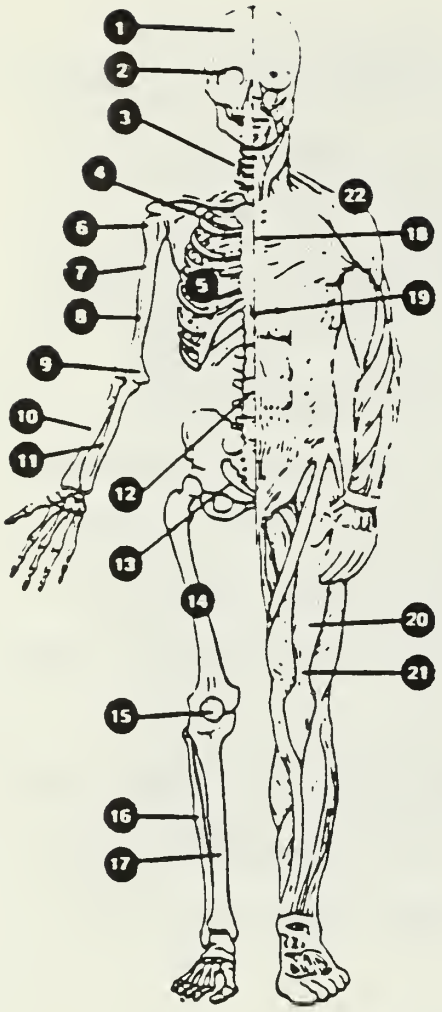


Fig. 11 Musculoskeletal System (Anterior View)

Body shape and support, protection of internal organs, and locomotion are but three of the functions of the musculoskeletal system.

1 Cranium
2 Bony orbit
3 Cervical vertebrae
4 Costal cartilage
5 Ribs
6 Humeral epiphysis
7 Humerus
8 Humeral diaphysis
9 Humeral metaphysis
10 Radius
11 Ulna
12 Lumbar vertebrae
13 Pelvis
14 Femur
15 Patella
16 Fibula
17 Tibia
18 Sternum
19 Xiphoid cartilage
20 Rectus femoris muscle
21 Patellar tendon
22 Deltoid muscle

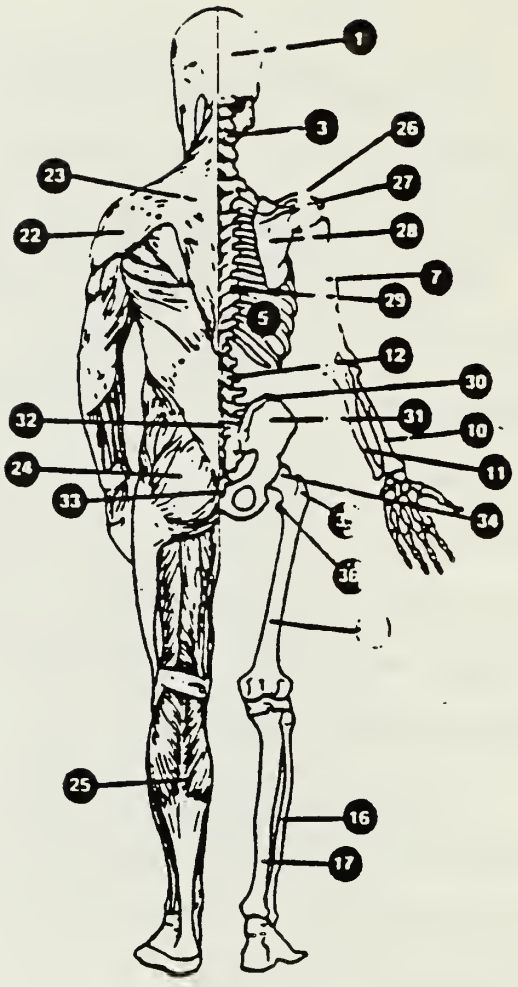


Fig. 12 Human Skeleton (Posterior View)

1 Cranium
3 Cervical vertebrae
5 Ribs
7 Humerus
10 Radius
11 Ulna
12 Thoracic vertebrae
14 Femur
16 Fibula
17 Tibia
22 Deltoid muscle
23 Trapezius muscle
24 Gluteus maximus muscle
25 Gastrocnemius muscle
26 Clavicle
27 Acromion
28 Scapula
29 Thoracic vertebrae
30 Iliac crest
31 Ilium
32 Sacrum
33 Coccyx
34 Head of femur
35 Greater trochanter
36 Lesser trochanter

Young Children with Cerebral Palsy: Practical Guidelines for Care

Shirley Steele

Although cerebral palsy is not a progressive disorder, secondary complications, such as contractures and deformities, may result. To minimize such complications, nurses can teach parents effective positioning and handling methods.

Neuromotor status is based on an assessment of the infant's posture, locomotion, movement control, muscle tone, coordination, manipulation, and reflexes. Cerebral palsy illustrates a condition manifested by interferences with movement control. Because the infant's reflexes provide early indications of neuromotor dysfunction, the nursing assessment should focus on these reflexes.

Children with cerebral palsy usually receive care from interdisciplinary health-care teams and their families. Nurses have a marvelous opportunity for contribution by assessing neuromotor function and interpreting findings for the family. To do this effectively, nurses must understand neuromotor development and offer practical guidelines for promoting development and preventing secondary complications.

Factors Contributing to Cerebral Palsy

Many factors contribute to congenital cerebral palsy. Three significant factors include asphyxia, prematurity, and bleeding during the first trimester of pregnancy. Asphyxia, implicated in 40% of congenital cerebral palsy cases, usually causes spastic tetraplegia. Prematurity, occurring in 37% of the cases, also frequently causes spastic diplegia. Bleeding during the first trimester is noted to occur in about 11% of the cases. In 44% of the children with congenital hemiplegias and 34% of those with ataxic syndromes, no complications of pregnancy and/or delivery are noted (Fritsch & Haidvage, 1982).

Classifications of Cerebral Palsy

Historically, a variety of classification systems have been used to describe cerebral palsy. A current topographical classification is found in Table 1 (Bleck & Nagel, 1975).

In addition to the categories listed in Table 1, the neuromotor status of cerebral palsy is usually classified as one of three types: spastic, dyskinesis (athetoid), or mixed including ataxic (Bleck, 1979). The motor characteristics of the two most common types, spastic and dyskinesis (accounting for 65% to 70% of cases), are quite dissimilar (see Tables 2 and 3).

Table 1. Topographical Classification of Cerebral Palsy
(Adapted from Bleck & Nagel, 1975, p. 38)

Type	Definition
Monoplegia	One extremity involved
Diplegia	Lower extremity involved; sometimes upper extremity involved
Hemiplegia	One side of body affected
Triplegia	Three extremities involved
Paraplegia	Both lower extremities involved
Quadriplegia	All four extremities involved

Motor Patterns

Because all behavior requires movement, deviations in motor patterns are the most prominent signs of neurologic impairment in young children. Whether a neuromotor pattern is normal or abnormal partially depends on the infant's age. Therefore, the infant's age and anticipated motor development must be known prior to assessment.

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Table 2. Primary Characteristics of Spastic Cerebral Palsy
(Adapted from Zelle & Coyner, 1983, p. 423)

- Hypertonus
- Hyperactive stretch reflex
- Increased tendon jerks
- Occasional clonus and other signs of upper neuron lesions
- Abnormal postures that may become fixed deformities or contractures
- Possibly labored voluntary movements
- Arm pattern: flexion-adduction with internal rotation and pronation of elbow
- Hip: flexion-adduction with internal rotation
- Inability to move isolated joints: mass movements

Table 3. Main Motor Characteristics: Dyskinesis (Extrapyramidal) Cerebral Palsy
(Adapted from Zelle & Coyner, 1983, p. 425)

- Bizarre, purposeless movements
- Involuntary movements increased by excitement
- Voluntary movements greatly impaired; lack of fine movements
- Either hypo- or hypertonia
- Possible inability to maintain weight
- Possible paralysis of gaze movements, difficulty looking upward, or inability to close eyes voluntarily

Table 4. Assessment of Primitive Spinal Reflexes
(Adapted from Fiorentino, 1973, p. 8)

- **Flexor Withdrawal**
  Test position — supine, head midposition, legs extended.
  Stimulus — scratch to sole of foot.
  Positive reaction — flexion of stimulated extremity.
- **Extensor Thrust**
  Test position — supine, head midposition, one leg extended, the other leg flexed.
  Stimulus — scratch ball of foot of flexed leg.
  Positive reaction — uncontrollable extension of stimulated leg.
- **Cross Extension**
  Test position — supine, head midposition, both legs extended.
  Stimulus — tap on medial adductor area of thigh.
  Positive reaction — opposite leg adducts and internally rotates, and foot plantar flexes.
- **Palmar Grasp Reflex**
  Test position — any position.
  Stimulus — pressure to palm of hand.
  Positive reaction — tight grasp of fist.
- **Myotatic Reflex (Stretch Reflex)**
  Test position — dependent on muscle tendon stretched.
  Stimulus — quick stretch (tap) on muscle tendon.
  Positive reaction — quick muscle contraction.

Children with cerebral palsy are at a disadvantage because they almost always have both motor deviations and motor delays. They also can experience sequential changes of muscle tone over time. For example, a gradual change may occur from an original condition of hypotonia to spasticity. The hypotonic stage may last from 6 weeks to 17 or more months. Generally, the longer the hypotonic period lasts, the more severely disabled the child (Menkes, 1980). Periodic evaluations are needed to identify these changes in neuromotor deviations. The child's progress must be followed to encourage ordinary developmental patterns and to provide compensatory mechanisms for motor disorders that cannot be alleviated.

Primitive Motor Reflexes

Reflexes are involuntary actions that are the newborn's earliest movements. Reflexes can be elicited by a variety of stimuli. Three factors that determine whether or not a given reflex can be elicited are: (a) the maturation level of the nervous system, (b) the structural integrity of the nervous system, and (c) the infant's physiologic condition at the time of testing (Lenz, 1973).

Soon after birth, the infant's neurologic status must be assessed through evaluation of a set of reflexes. Neurologic dysfunction is suspected if the reflex is uneven in strength when elicited on both sides of the body, or the reflex is too weak or too strong (Connor, Williamson, & Siepp, 1978). As the child matures, neurologic dysfunction is suspected when: (a) A normal newborn reflex continues for too long. (b) an ordinary reflex fails to appear at the anticipated time, or (c) a reflex does not appear at all. During the newborn period, segmental reflexes, such as coughing and sucking, should also be evaluated.

At least one authority (Wyke, 1975) emphasizes that neurologic mechanisms producing and controlling body movements during the infant's first year are entirely reflexive. He suggests infants respond to mechanical and chemical stimuli rather than move at will. The infant is essentially a reflex machine whose neuromuscular behavior expresses the degree of differentiation and maturation of the various reflex systems. Although other authorities do not completely agree with Wyke, this stage of development is characterized by more reflexive behavior than at any other time.

Maturation and improvement in the infant's motor function depends upon the gradual increase in influence of higher central nervous system centers that impose control over lower centers. The higher level control involves inhibiting lower responses and modifying them into new and more appropriate motor responses. Maturations of higher centers depend upon the infant's ability to receive, transmit through the nervous system, and integrate sensory information at appropriate levels of the brain and spinal cord. As sensory messages are integrated at higher brain levels, motor responses are expressed accordingly (Connor et al., 1978; Haynes, 1983; Holt, 1975).

Children with cerebral palsy often have defects that interfere with the effective integration of sensory information at higher levels. This results in motor responses more consistent with lower level functioning. Movements deprived of higher level control are manifested as stereotyped, atypical movements connected with an abnormal quality of muscle tone (Connor et al., 1978). Only when the infant is released from domination by the tonic-neck-reflex at 4 months of age does adaptive behavior adequately demonstrate cortical intactness predictive of later behavior. So definitive diagnosis of impairment may be difficult before this age. Testing routines for the common primitive reflexes indicating central nervous system intactness are found in Tables 4 through 7.

Developmental Timetable for Common Reflexes

According to Accardo and Capute (1979), motor pattern evaluation is the most important aspect of the early diagnostic evaluation of the child. Early diagnosis can contribute to a more positive treatment outcome. The goal of treatment is to reduce the primary disability through facilitating expected developmental tasks and preventing or slowing the development of complications. Facilitating functional movement patterns prevents muscles and joints from losing movement ability, fosters postural reflexes, and inhibits primitive motor patterns from persisting beyond their normal time frames. Table 8 presents guidelines about when common reflexes are expected to appear and disappear.

Postural Effects of Reflexes

The infant's posture and movements are influenced by primitive reflexes. The primitive reflexes are thought to be residual fetal patterns used to prepare the infant for the birthing process. These reflexes play a role in the newborn's development and adaptation to the environment. The reflexes are neuromuscular responses that contribute to the infant's postural stability and motor patterns. Because these reflexes are variable and modifiable, they must be addressed in the therapy of infants with developmental disabilities.

The normal newborn will probably assume a flexed position of both the upper and lower extremities because the flexor (ventral) muscles are more active than extensor (dorsal) muscles. Flexor tone is generally lost in the upper extremities by 4 months of age and shortly after 4 months in the lower extremities (Menkes, 1980).

Gravity affects the infant's movements from birth. Gravity stimulates a tonic labyrinthine motor reflex when the infant is prone thereby exaggerating a flexor posture. If the infant is placed in a supine position, the tonic labyrinthine reflex stimulates extensors that decrease the exaggerated flexor posture (Zelle, 1983). Because of the infant's immature neuromotor system, the infant depends on others' full postural support to counteract gravity.

When a stimulus is applied to the foot, the infant responds by flexing the legs (flexor withdrawal reflex). The rooting reflex, stimulated by touching the lips, causes the infant to move the head toward the stimulated side. This makes it possible for the infant to move to the nipple for feeding. The protective and rooting responses are precursors to rotation patterns.

The primitive reflexes assume additional importance when an infant cannot inhibit these early movements because of immature neuronal networks that may be present at birth and persist indefinitely.

An infant with a serious brain injury can present with hypotonia. During the evaluation, the infant's palmar and plantar grasps may be weak; the Moro reflex, absent; and the placing and stepping reflexes, difficult to elicit.

An infant who has experienced serious perinatal hypoxia may exhibit hypertonia and rigidity. The infant's evaluation may reveal that deep tendon reflexes are depressed because of rigidity. Hyperreflexia appears later in the first year.

Direction of Development

Infants' neurologic development proceeds in cephalocaudal and proximodistal directions. The nervous system's functional maturity is related to a myelinization process in which a fatty sheath forms around nerve fibers. Myelinization reflects maturation level of the nervous system. The importance of assessing normal cephalocaudal development is illustrated when a hypotonic 2 month old, without progressive disease of central origin, develops motor con-

Table 5. Assessment of Primitive Brainstem Reflexes
(Adapted from Fiorentino, 1973, p. 13)

- **Asymmetrical Tonic Neck (ATNR)**
  Test position — supine, head midposition, arms and legs extended.
  Stimulus — turn head to one side.
  Positive reaction — the upper extremity on side turned to extends, the one on opposite side flexes (fencing position).
- **Symmetrical Tonic Neck (STNR)**
  Test position — prone across examiner's knees (on all fours).
  Stimulus — (a) passive flexion of head.
  (b) passive extension of head.
  Positive reaction to — (a) flexion of arms and extension of legs.
  (b) extension of arms and flexion of legs.
- **Tonic Labyrinthine (TLR)**
  (a) Supine
  Test position — supine, head midposition, arms and legs extended.
  Stimulus — the stimulus *is the supine* position.
  Positive reaction — increased extensor tone.
  (b) Prone
  Test position — prone, head midposition.
  Stimulus — the stimulus *is the prone* position.
  Positive reaction — increased flexor tone.
- **Positive Supporting Reaction (PS)**
  Test position — hold child in standing position.
  Stimulus — bounce on soles of feet.
  Positive reaction — increase in extensor tone of legs with plantar flexion as soles are stimulated by pressure.

Table 6. Assessment of Midbrain Reflexes[a]
(Adapted from Fiorentino, 1973, p. 22)

- **Neck Righting**
  Test position — supine, head midposition, arms and legs extended.
  Stimulus — rotate head to one side.
  Positive reaction — body will roll as a whole to side to which head is turned.
- **Body Righting Acting on the Body**
  Test position — supine, head midposition, arms and legs extended.
  Stimulus — rotate head to one side.
  Positive reaction — segmental rotation of body.
- **Amphibian Reaction**
  Test position — prone, head in midline, legs extended, and arms over head.
  Stimulus — left pelvis on one side (should be a quick stretch).
  Positive reaction — automatic flexion of extremities on that side.

[a]Midbrain level reflexes (righting reactions) peak at 10 to 12 months of age.

Table 7. Automatic Movement Reactions After Semicircular Canal Stimulation
(Adapted from Fiorentino, 1973, p. 34)

- **Moro Reflex (Startle Reflex)**
  Test position — supine, head midposition, extremities extended.
  Stimulus — loud noise.
  Positive reaction — quick extension and abduction of arms by slower flexion and abduction.
- **Landau Reflex**
  Test position — hold child prone in space.
  Stimulus — (a) passive extension of neck.
  (b) passive flexion of neck.
  Positive reaction — (a) arms, trunk, and legs extend.
  (b) arms, trunk, and legs flex.
- **Protective Thrust Reflex**
  Test position — hold child prone, suspend head downward.
  Stimulus — thrust head toward floor.
  Positive reaction — arms and head extend.
- **Lift Reaction**
  Test position — hand and knee position on a movable table.
  Stimulus — (a) move table up.
  (b) move table down.
  Positive reaction — (a) when table starts up, the head and arms flex; when stopped, the head and arms extend.
  (b) when table starts down, the head and arms extend; when stopped, the head and arms flex.

trol as expected and walks independently by 2 years of age (Knobloch & Pasamanick, 1974). In this example, neuromotor development proceeded in the anticipated sequence despite early signs of impairment.

Responses to Stimuli

Although the infant with a neurologically intact system cannot inhibit all noxious stimuli, the infant is able to eventually shut out repeated, unpleasant stimuli. The infant soon learns which stimuli are positive and which ones are not. As the neuronal networks mature, the infant develops internal regulatory mechanisms that reduce energy states. However, the infant with cerebral palsy may have faulty internal regulatory mechanisms that may cause a lowered or increased response threshold to stimuli. Interferences with eating, sleeping, breathing, or ability to be comforted may result. Therefore, the infant who has difficulty responding to stimuli appropriately is likely to become frustrated.

The infant's integration of stimuli is a complicated process. The ability to integrate these stimuli in meaningful ways is an index of the intactness of the infant's cerebral cortex.

Components of Care

Four major objectives of care for these children are: (a) to inhibit abnormal tone associated with abnormal movement patterns and abnormal posture, (b) to provide a variety of sensory stimulation and thus foster more normal movements, (c) to enhance the development of mature postural reflexes, and (d) to plan activities based on anticipated developmental milestones.

Parents are taught management strategies so that the program of care can be continued throughout each day. Parents are also taught positioning needs and play strate-

Table 8. Developmental Timetable Regarding Common Reflexes
(Adapted from Menkes, 1980, p. 247)

Age (Months)	Appearance of Reflexes	Disappearance of Reflexes
0-1	Moro; palmar, plantar, grasp; weak tonic neck; stretch; rooting; positive supporting action.	
1-2	Stronger tonic neck.	
2-3		Neonatal reflexes start to disappear.
3-5	Tonic neck may be present. Plantar grasp.	Other neonatal reflexes disappear (except plantar grasp).
4-8	Neck righting.	
5-6	Tonic neck may be present. Plantar grasp usually presen	All other neonatal reflexes except for tonic neck should be gone; any remaining are abnormal.
7-8	Uses arms for protection towards sides.	
7-9	Parachute response present	Remaining tonic neck is now abnormal.
12-18		Plantar grasp disappears.

Fig [illegible]. *The child is positioned over the adult's body to bring the arms forward and encourage use of weak neck muscles. This position also encourages relaxation of hypertonic muscles. A favorite toy placed on the floor can capture the child's attention.*

Figure 3. *The child is placed in a sitting position with the adult's hand placed on the abdominal or thoracic region to facilitate rotational movements. A musical toy is used to gain the child's attention.*

Figure 2. *The adult lies on the floor in order to support some of the child's weight, relieving the weight bearing from the elbow and forearm. This position can also encourage eye-to-eye contact.*

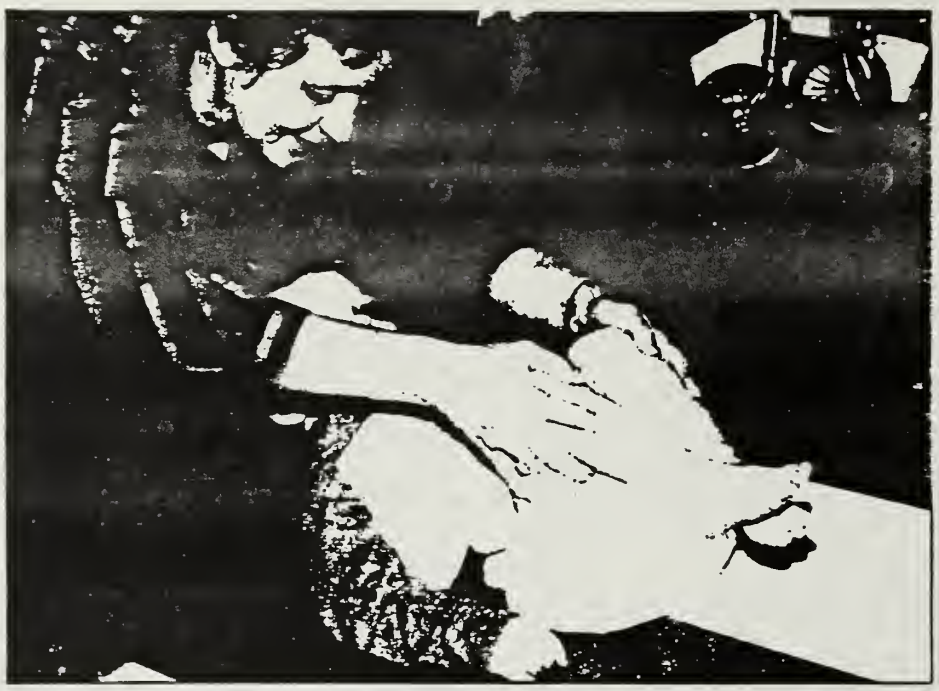

Figure 4. *The child is placed in a position to facilitate flexion.*

Figure 5(A). *Flexion is encouraged by the adult crossing her legs and placing the child's legs over the adult's legs. Note that in this sequence the child's fingers are still hyperextended.*

Figure 5(B). *Note that the child's body is now flexed, including the fingers.*

Figure 6(A). *If the child is not positioned correctly, he or she will assume this extensor pattern, including scissoring of the feet.*

Figure 6(B). *When positioned correctly, the child assumes a more normal flexed position.*

Figure 7. *The "en face" position is used to strengthen the neck flexor muscles.*

Figure 8. *Discourage the child with hypotonia from assuming this abnormal W-shaped seating position.*

Figure 9. *Carrying the child with your arms between the child's legs can compensate for tight adductors.*

gies to facilitate the child's development and to provide sensory stimulation.

Positioning suggestions. Each positioning intervention is designed to: (a) keep the child's body in alignment, (b) promote symmetry of function, (c) make the child comfortable, and (d) ensure safety. Positioning methods that can help a child with dysfunction achieve these goals include the following:

1. Position the child prone over a wedge, bolster, or adult's body in such a way as to bring the child's arms forward. The prone position:
   a. encourages head righting, uses gravity as the stimulator for weak neck extensors, and thus helps to stimulate head control (see Figure 1).
   b. encourages integration of the tonic labyrinthine prone reflex, labyrinthine righting acting on the head reflex, and the asymmetrical tonic neck reflex.
   c. encourages eye-hand association.
   d. encourages scapula stability.
   e. discourages scapula abduction (round shoulders).
2. Relieve some of the weight on the child's elbows and forearms by having the child lie on top of the adult who can support some of the child's weight with hands placed appropriately (see Figure 2).
3. Place a bolster between the child's legs to maintain range of motion gained from rotation (especially useful for children with spasticity).
4. Use the side-lying position to encourage flexion of the "up" side of the body and extension of the "down" side of the body (especially useful for children with dyskinesis [athetosis]). This position encourages adduction of the legs and offers a position of stability.
5. The supine position is used less often and is only chosen for a clearly defined purpose. When used, the supine position:
   a. encourages integration of the tonic labyrinthine supine reflex.
   b. facilitates rotation to break up spasticity.
   c. can be used with bolsters to flex the head, hips, and knees to encourage a stronger flexor pattern.
6. When a child lacks the ability to sit, corner sitting can provide stability. This is especially useful for children with dyskinesis (athetosis).
7. Side sitting, Indian sitting, and long sitting are other alternatives. Side sitting and Indian sitting are only encouraged if no flexor spasticity in the knees exists.
8. The sitting position is used to facilitate rotational movement (see Figure 3).
9. The child is placed in a supine position with the head slightly elevated and the legs flexed to discourage extensor patterns (see Figure 4).
10. The child is placed on the adult's lap to encourage a flexed position. Note in Figure 5A that the child's fingers are still hyperextended; in Figure 5B, flexion occurs.
11. By sitting on the floor, the adult can encourage flexion of the child's body and hopefully overcome the child's tendency to use extensor patterns. See Figures 6A and 6B.
12. The adult places the child in an "en face" position to strengthen the neck flexor muscles (see Figure 7).
13. The position that is consistently *discouraged* is the W-shaped sitting position that is frequently assumed by these children (see Figure 8).
14. Remember that similar to the neurologically intact child's need for frequent position changes, children with disabilities also need frequent position changes.

Carrying suggestions. The child can be carried in a variety of ways to facilitate better body alignment and discourage faulty reflex positioning:

1. The child's postural stability must be encouraged.
2. Carry the child in a prone position if the child has inadequate head control.
3. Place your arms between the child's legs if the child has tight adductors (see Figure 9).
4. If the child has extension problems, use rotation to bring the child to a sitting position before carrying, and then carry the child in a sitting position.
5. Bend the child with spasticity forward at the hips, and sit the child up before lifting.
6. Carry the child with dyskinesis (athetosis) in a sitting position while controlling arm and leg movements.

Methods to be avoided. Certain approaches should be avoided in positioning and handling these children:

1. Avoid bouncing children with your hands under the armpits. Instead, use techniques suggested in the position section.
2. Avoid forcing extremities into desired positions. Instead, use facilitation techniques, such as rotation, to achieve desired positions.
3. Avoid lifting the children with your hands under the armpits. Instead, use techniques suggested in the positioning section.
4. Avoid placing the children in the supine position for extended periods. The prone position is generally more therapeutic.
5. Avoid throwing the child in the air even if the child seems to enjoy it. Instead, swing the child slowly while in a flexed position.
6. Sudden jerky, unannounced touching of the children tends to cause them to have abnormal movements. First,

tell the children what you are going to do; and then proceed slowly and smoothly.

Play strategies: Teaching loops can help parents improve play outcomes. A teaching loop includes: getting the child's attention, demonstrating the play, giving the child an opportunity to return the demonstration, and rewarding the child for efforts (Bee, 1980). Using the teaching loops, parents can engage the child in stimulating play activities while keeping the child in an appropriate position. Using play to increase sensory awareness, the child is happier and more cooperative while correctly positioned. Both the parents and the child need to understand what is expected of them so that positive interactions occur and development is fostered while attention is being focused on the child's movement.

Preventing secondary problems. Although cerebral palsy is not a progressive disorder, the child's condition may appear to worsen with increasing age as the consequences of the brain injury are reflected in delayed, asymmetrical, or disordered motor development. The brain injury interferes with the child's ability to impose inhibitory control over responses. Movement responses deprived of higher-level brain control are manifested as motor patterns that are stereotyped, atypical, and associated with abnormal muscle tone.

If the child consistently uses aberrant movement patterns with abnormal tone, secondary disabilities, such as contractures and deformities, may develop and tend to exaggerate the child's primary problem. Because secondary problems can discourage the family, counseling, education, and anticipatory guidance are critical to the child's healthcare plan. PSD

REFERENCES

Accardo, P.J., & Capute, A.J. (1979). *The pediatrician and the developmentally delayed child.* Baltimore: University Park Press.

Bee, H.L. (1980). The teaching interaction: Some history and basic concepts. In K E. Barnard (Ed.), *Nursing child assessment satellite training* (pp. 131-138). Seattle: University of Washington.

Bleck, E.E. (1979) *Orthopedic management of cerebral palsy.* Philadelphia: W.B. Saunders.

Bleck, E.E., & Nagel, D.A. (1975). *Physically handicapped children — A medical atlas for teachers.* New York: Grune & Stratton.

Connor, F.P., Williamson, G.G., & Siepp, J.H. (1978). *Program guide for infants and toddlers with neuromotor and other disabilities.* New York: Teachers College Press.

Fiorentino, M.R. (1973). *Reflex testing methods for evaluating central nervous system development* (2nd ed.). Springfield, IL: Charles C. Thomas.

Fritsch, G., & Haidvage, M. (1982). Pre- and perinatal risk factors in the etiology of infantile cerebral palsy. *International Journal of Rehabilitation Research, 5,* 19-26.

Haynes, U. (1983). *Holistic health care for children with developmental disabilities.* Baltimore: University Park Press.

Holt, K.S. (1975) How and why children move. In K.S. Holt (Ed.), *Movement and child development,* (pp. 1-7). Philadelphia: J.B. Lippincott.

Knobloch, H., & Pasamanick, B. (1974). Neuromotor dysfunction. In H. Knobloch & B. Pasamanik (Eds.), *Developmental diagnosis* (3rd ed.). (pp. 209-232). Hagerstown, MD: Harper and Row.

Lenz, E. (1973). *Reflexes in the infant, Part I.* Baltimore: University of Maryland.

Menkes, J.H. (1980). *Child neurology* (2nd ed.). Philadelphia: Lea and Febiger.

Wyke, B. (1975). The neurological basis of movement — A developmental review. In K.S. Holt (Ed.), *Movement and child development* (pp. 19-33). Philadelphia: J.B. Lippincott.

Zelle, R.S. (1983). Meeting developmental and habilitative needs of infants and toddlers. In R.S. Zelle & A.B. Coyner (Eds.), *Developmentally disabled infants and toddlers: Assessment and intervention* (pp. 61-77). Philadelphia: F.A. Davis.

Zelle, R.S., & Coyner, A.B., (Eds.). (1983). *Developmentally disabled infants and toddlers: Assessment and intervention.* Philadelphia: F.A. Davis.

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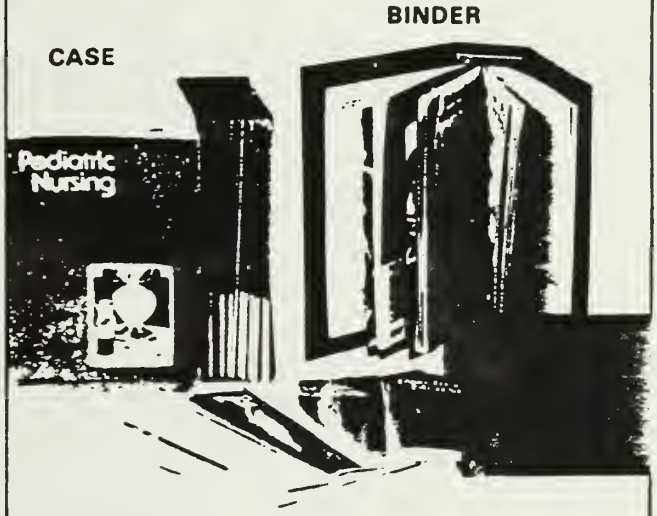

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ATYPICAL MOTOR DEVELOPMENT

Objectives

After completing this unit, participants will:

1. Identify the types of cerebral palsy.
2. Be able to handle and position a child with abnormal nuscle tone and understand the reasons for doing so.
3. Become familiar with adaptive equipment used in the care of children who have atypical motor development.
4. Become familiar with the latest research, especially with regard to surgical procedures

ATYPICAL MOTOR DEVELOPMENT

Outline -- Western Region

Presented by Julie Rutkowski, M.S., R.P.T.

Massachusetts Department of Public Health

A. The Best Tool for Recognizing Motor Problems is Observation

B. Normal Development Versus Abnormal Development

C. Two Point Goal for Health Providers:

   1. Avoid exaggerating, or actively reduce, presenting pathological symptoms

   2. Once the symptoms are reduced, enhance natural movement thereby natural feedback, for more normal development

D. Cerebral palsy is, by definition, a static brain lesion, however, the symptoms are progressive.

E. Five Symptom Categories in the Spastic Cerebral Palsy Child:

   1. Reflexes -- primitive reflexes persist

   2. Tone -- high

   3. Function ability -- delayed, blocked, or abnormal

   4. Posturing -- stereotypic and synergistic

   5. Symmetry - body aligned asymmetrically

F. Supine Lying

   1. Reflexive extensor tone

   2. Function severely impeded

   3. ATNR, Asymmetry, Scoliosis, Hip Subluxation

   4. Typical Posturing: Reverse T, Frog, Scissoring, Windblown

(continued)

G. Prone Lying

1. Reflexive Flexor Tone

2. Positive for Promoting Postural Extension

H. Sitting

1. Underdeveloped postural mechanisms; back rounded, slouched

2. Reflex -- Extensor thrust

3. Spastic resistance to break up total body patterns

4. Asymmetry, particularly in hemiplegia

5. Avoid W-sitting

I. "Magic Angles" -- tonal switches impact around a 90 degree angle.

J. Rotation

1. By definition, a combination of flexion and extension

2. Valuable handling tool to interrupt spastic fixing

K. Postural Dependency

1. Dependent babies can mold into deformity

2. Perpetuation of typical spastic posturing

3. Movement or position alien to a spastic synergy weakens it

L. Preparation for Different Positions

1. Anticipating next position in transition handling

2. Appreciating child's reaction to assistance given

M. Upright Position

1. Highest developmental level

2. Hardest to avoid pathological symptoms

3. Reflex - extensor thrust

4. Neural overflow and cross influence

5. Aim is for <u>quality</u> performance upright

N. Joint Range of Motion

BIBLIOGRAPHY

1. Bishop, Beverly. Spasticity: It's Physiology and Management. Physical Therapy, Volume 57, No. 4, 371 - 401, 1977.

2. Bobath, Berta. Abnormal Postural Reflex Activity Caused by Brain Lesions. London: William Heinemann Medical Books Limited, 1971.

3. Bobath, Berta and Bobath, Karel. Motor Development in the Different Types of Cerebral Palsy. London: William Heinemann Medical Books Limited, 1975.

4. Bobath, K. The Neuropathology of Cerebral Palsy and Its Importance in Treatment and Diagnosis. Cerebral Palsy Bulletin, Vol. 1, No. 8, 13- 33, 1959.

5. Delong, M. Central Patterning of Movement. In E. V. Evans et al. Central Control of Movement. Neurosciences Research Program Bulletin, 10- 30, 1971.

6. Downey, John A., and Darling, Robert C. Physiological Basis of Rehabilitative Medicine. Philadelphia: W.B. Saunders Co., 1971.

7. Fiorentino, M. Reflex Testing Methods for Evaluating CNS Development. Springfield, IL, Charles C. Thomas Publisher, 1963.

8. Gardner, Elizabeth B. and O'Connell, Alice L. Understanding the Scientific Basis of Human Movement. The Williams & Wilkins Co., Baltimore, 1972.

9. Gesell, A., Amatruda, C. Developmental Diagnosis. New York, Paul B. Hoeber Inc., 1949.

10. Hoskins, Theresa A., and Squires, Janet E. Developmental Assessment: A Test for Gross Motor and Reflex Development. Physical Therapy, Vol. 53, No. 2, 117 - 126, 1973.

11. Houk, J., Singer, Joshua and Henneman, Elwood. Adequate Stimulus for Tendon Organs with Observations on Mechanics of Ankle Joint. J. Neurophysiology, 34, 1051 - 1065, 1971.

12. Janson, Jan K. S. Spasticity - Functional Aspects. Acta. Neurol. Scandinav, Suppl. 3, Vol. 38, 41 - 51, 1962.

13. Kong, E. Early Treatment of the Motor Handicap. In Syllabus of Instructional Courses, Academy for Cerebral Palsy 26th Annual Meeting. 141 - 144, 1972.

14. Piaget, J. The Origin of Intelligence in Children. New York, International Univ. Press, 1952.

15. Prechtl, Heinz and Beintema, David. The Neurological Examination of the Full Term Newborn Infant. Little Club Clinics in Developmental Medicine No. 12, London: National Spastics Society, 1964.

16. Rood, M. Unpublished Notes from the Treatment of Neuromuscular Dysfunction Workshop: Rood Approach, Instructional Course, Mass. APTA, July 1976.

17. Saint-Anne Dargassies S. The Development of the Nervous System in the Foetus. Monograph available from the author, Central Neonatal de l'Association Claude Bernard, 123 Boulevard de Port-Royal, 75014, Paris, France; Switzerland, Nestle.

18. Salek, Barbro. A General Overview of Developmental Disabilities Part I: Philosophical Aspects of Assessment and Intervention From A Multidisciplinary Standpoint. In Developmental Disabilities Workshop, A Management Approach, Dept., Ex. Sci., Univ. of Mass., 3 - 9, 1975.

19. Taub, E. and Berman, A. J. Movement and Learning in the Absence of Sensory Feedback. In S. J. Freedman, The Neuropsychology of Spatially Oriented Behavior, Homewood IL, Dorsey Press, 173 - 191, 1968.

20. Tokizane, Toshihiko, Murao, Mc' to, Ogata, Tamotsu, and Kondo, Tatsuko. Electromyographic Studies on Tonic Neck, Lumbar, and Labyrinthine Reflexes in Normal Persons. Jap. J. Physiol., Vol. 2, 130 - 146, 1951.

21. Weisz, Stephen. Studies in Equilibrium Reaction. J. Nerv. Ment. Dis., Vol. 88, 150 - 162, 1938.

22. Wilder, J. Dasimetric Approach (Law of Initial Value) To Biological Rhythms. Annals N. Y. Acad. Sci., Vol. 98, Art. 4, 1211 - 1220, 1962.

BASIC DIFFERENCES BETWEEN SPASTICS AND ATHETOIDS

SPASTICS	ATHETOIDS
Usually hypertone.	Fluctuating tone.
Poverty of movements of midranges in predictable spastic patterns.	Variety of movements of extreme ranges in not so predictable patterns.
Exaggerated co-contraction particularly at proximal joints.	Lack of co-contraction and proximal fixation.
Greater danger of deformities.	Less danger of deformities.

AIMS OF TREATMENT

SPASTIC	ATHETOID
Reduction of hypertonus to give a background of a more normal muscle tone. Use proximal body parts to control the child, (hips/ shoulders/trunk).	Increase low tone but be wary of over increase.
Facilitate righting, equilibrium and other automatic reactions.	Use weight bearing, pressure, resistance and intentioned learning to achieve normalized movement.
Aim at wide range movements with voluntary initiation providing they are within normal type movements.	Work for sustained postural tone and good fixation.
Build up, teach, normal movement sequences, e.g. coming from kneel to standing with foot forward.	Much emphasis on control through head/shoulder girdle and arms.
Prevent associated reactions.	Symmetry.
Work on weight bearing (arms and legs) then to stepping or placing.	Holding of mid ranges of movement.
Avoid resistance to movement. Avoid effort on the part of the child. These increase spasticity.	
Prevent contractures and deformities.	
Handling is treatment.	

Cerebral Palsy

Alfred Healy, M.D.

DESCRIPTION

Cerebral palsy (CP), sometimes called chronic, nonprogressive neurologic injury, is a disorder of muscle control or coordination resulting from injury to the brain during its early (fetal, perinatal, and early childhood) stages of development. There may be associated problems with intellectual, visual, or other functions.

With cerebral palsy, the problem lies in the brain's inability to control the muscles; the muscles themselves and the nerves connecting them to the spinal cord are perfectly normal. The extent and location of brain injury determine the type and distribution of CP:

Spasticity

Stiffness of the muscles (hypertonia) occurs when the injury is on the brain surface (motor cortex) or when it involves those nerves leading from the surface through the substance of the brain (corticospinal, or pyramidal, tract) and into the spinal cord. Spasticity is present in about 60 percent of all cases of cerebral palsy.

Dyskinesia

This type, which accounts for roughly 20 percent of all cases of cerebral palsy, is caused by injury to the basal ganglia area, the brain's motor switchboard. Dyskinesia is a term describing the unwanted, involuntary movements of cerebral palsy. These include slow, writhing movements, particularly of the wrist and fingers (athetosis), which may be accompanied by more abrupt and jerky movements (choreoathetosis). Another form of dyskinesia is comprised of slow, rhythmic movements involving the trunk or an entire extremity (dystonia). All three forms are more prominent with voluntary activity or emotional stress. Dyskinesia is sometimes accompanied by increased muscle tone, or "tension," which also varies with body position and emotional state.

Ataxia

Occurring by itself in about 1 percent of all cerebral palsy, ataxia is characterized by a broad-based, lurching gait with primary balance difficulties. The injury is in the cerebellum.

Mixed

Approximately 30 percent of individuals with cerebral palsy have a combination of spasticity and dyskinesia or ataxia, with one type predominating.

With the spastic type of CP, the following terms are used to denote which parts of the body are affected:

- ***Dipelgia***—Involvement of the trunk and all four extremeties—the legs more so than the arms
- ***Hemiplegia***—Involvement of one side of the body only
- ***Paraplegia***—Involvement of the legs only
- ***Quadriplegia***—Involvement of both arms, both legs, the head, and the trunk

There are also cases of mono*plegia*—involvement of one extremity—and *triplegia*—involvement of three extremities; but these are unusual.

Some children with cerebral palsy have severe disabilities; others have barely detectable problems with muscle control. There is no universally used, objective method by which physicians or therapists can adequately categorize patients as having mild, moderate, or severe degrees of motor dysfunction. Such estimates are usually made subjectively.

CAUSE

Cerebral palsy results from brain injury due to such events as a stroke during fetal life, lack of oxygen at birth, and intracranial hemorrhage or meningitis during infancy. In as many as 50 percent of the cases, the specific cause of the injury is not evident.

The type of CP is related to three factors: the causal event, the timing of this event, and the location of the damage. For example, an intracranial hemorrhage in a susceptible premature infant may damage the corticospinal and associated tracts, causing spasticity. Or high levels of bilirubin—a product of the breakdown of red blood cells—may damage the basal ganglia in newborns, resulting in athetosis.

INCIDENCE

The incidence of cerebral palsy varies with different studies. The most often quoted figure is 1.5 to 2 per thousand live births. The incidence is higher in areas where there is inadequate prenatal care and accompanying prematurity

DETECTION

The diagnosis of cerebral palsy is made on the basis of a history of delayed achievement of motor milestones, observation of abnormal movement, and abnormal findings in the physical examination (e.g., stiffness, very active knee jerks, persistent primitive reflexes).

Spasticity or dyskinesia are not always evident during the first few months of life. However, most cases of cerebral palsy can be detected by 12 months, nearly all by 18 months. Some children with abnormalities of posture and movement in the early months reportedly outgrow them; but this, except in mild cases, is rare.

Other factors besides insufficient age can make the diagnosis difficult. These include:

Prematurity

An infant born too early or too small must be given extra time to achieve certain skills. For example, the infant born two months early may be normal but just not sitting up within the normal range of expected times for full-term infants.

Extremes of normal range

Some babies sit at four months, others not until nine months; yet both groups may fall within the normal range. Only when the skill is not being performed after the outer limit of "normal" is reached or when there is a constellation of abnormal signs can we infer that something is wrong.

Quality of performance

Some infants have the ability to manipulate objects at the expected age, yet the manner in which they do so many indicate an abnormality. That is why experienced examiners must observe *how* as well as *when* infants perform motor activities. Since the diagnosis of cerebral palsy is based on clinical judgment and not on blood tests, X-rays, or the like, the observations of skilled examiners are necessary to make or confirm the diagnosis during infancy.

Effects of motor impairment

Children with cerebral palsy, like infants with general developmental delay, often do not perform expected motor tasks at age-appropriate times. It is critically important, however, to differentiate between these two groups of children. The basic indicator is that the generally developmentally delayed child's abilities are depressed in all areas, whereas the child with cerebral palsy may be very depressed in motor activities yet have good socialization and receptive language skills.

The belief that "they will grow out of it"

At times, parents are falsely reassured that, given time, an infant's motor delays will resolve on their own. Also, the physician may be reluctant to make a firm diagnosis of cerebral palsy on the basis of one office visit, particularly if the child is very young. If there is doubt, the wisest course is to reexamine the child at frequent intervals or to make a referral to persons highly experienced in developmental and neurological assessment. The advantages of early treatment if the child does have cerebral palsy—or the relief and reassurance if the child does not—are well worth the extra effort.

COURSE

During infancy, the manifestations of brain injury often change. The initially floppy (hypotonic) baby, for example, can later show signs of spasticity. Sometimes athetosis is not evident until the child is older. For this reason, diagnosis may not be exact in early infancy but may be revised as the child's neuromotor status evolves.

Cerebral palsy is the result of a permanent brain injury and is therefore lifelong. While the brain damage itself is nonprogressive, the resultant muscle control problems are not. However, their progress can be halted—or at least postponed—with proper therapy, including frequent elongation of stiff muscles and proper positioning. In some cases, surgery is necessary to release tight muscles and tendons, particularly of the ankles and hips, or to treat dislocations of the hips. Other orthopedic disorders, such as scoliosis and contractures of the joints, may become more problematic as the child gets older.

When appropriate therapy is available during the child's developing years, the parents can expect to see continued gains in muscle control, strength, and awareness of how certain motor skills are performed; such gains will result in improved ability to move, feed, dress, toilet, or communicate. The rate of this improvement, however, is greatly dependent upon the type of cerebral palsy, the way it is distributed, the degree of muscle involvement, and the presence of associated problems.

Children with cerebral palsy—provided they have comprehensive evaluation, care, and treatment—can look forward to an average longevity. All previous data supporting a shortened life span have been faulted by the inclusion of large numbers of individuals who, at an early age, were placed in institutions where they received less-than-adequate care.

ACCOMPANYING HEALTH PROBLEMS

Events causing brain injury around the time of birth are seldom so site-specific that they bring about only one kind of clinical problem. There are often injuries to different areas of the brain, each of which controls different functions. Associated problems include:

Mental retardation

Around 60 to 70 percent of all children with cerebral palsy are mentally retarded. This problem is seen less often with spastic diplegia.

Visual impairments

As many as 50 percent of all children with spastic cerebral palsy have an eye muscle imbalance problem; refractive errors are almost as common.

Hearing impairment

Cerebral palsy, particularly the type associated with brain damage due to excess bilirubin, may produce hearing deficits (hearing ability should therefore be carefully monitored). Also, children with motor problems may spend a large percentage of their time in a recumbent position; this makes them more susceptible to middle ear infections and persistent fluid in the middle ear, which can cause a conductive hearing loss.

Seizures

The brain injury which results in cerebral palsy often causes scarring on the cortex, a source of chronic irritation that may precipitate seizure activity in 35 to 45 percent (some studies report 60 percent) of persons with cerebral palsy. All types of seizures are reported, grand mal the most frequently.

MEDICAL MANAGEMENT

The interdisciplinary approach

Because the problems associated with cerebral palsy are numerous and complex, treatment involves the integrated efforts of specialists from many disciplines.

The physical therapist works to facilitate motor development, to prevent or slow orthopedic problems (such as limited range of motion or dislocation of joints), and to improve posture and positioning so that the child may more profitably engage in other types of intervention activities.

The occupational therapist teaches parents to handle the child's daily living activities—such as toileting, feeding, and dressing. (In many situations, this service is provided by or shared with the physical therapist.)

Both the physical and occupational therapists may help select appropriate equipment, such as special chairs and eating utensils, to facilitate independence and learning

The speech pathologist monitors the child's progress in speech and language skills. While it is unlikely that speech therapy *per se* will be initiated before age three, this specialist counsels parents and other therapists on how to stimulate language development and may also work with the occupational therapist in managing feeding problems.

Also important is the primary physician, who treats the usual childhood disorders and helps prevent many health problems from occurring. Depending on the nature of the associated problems, a variety of physician subspecialists may also be involved with the child—an orthopedist to prescribe braces or perform surgical procedures, an ophthalmologist to treat crossed eyes (strabismus), a neurologist to help control seizures.

Muscle relaxants

Certain drugs are helpful in cases of hypertonia. The three most commonly used are diazepam, dantrolene, and baclofen. Diazepam (Valium) acts on the central nervous system rather than directly on the muscle. This drug is useful for treating spinal cord injury as well as cerebral palsy. Diazepam may cause physical dependency and therefore should not be withdrawn suddenly.

Dantrolene (Dantrium) works directly on the muscle, reducing contraction. It is especially useful with children whose care is made difficult by prolonged muscle contraction and who will not be troubled by a reduction in voluntary muscle power. This drug may affect liver function; therefore, signs of jaundice should be reported immediately.

Baclofen (Lioresal) acts mainly on the spinal cord to relieve increased muscle tone and muscle spasms. It is used primarily with spinal cord lesions and occasionally for cerebral palsy. The most common side effect is sedation, which tends to disappear a few days after the initial doses.

IMPLICATIONS FOR EDUCATION

Some children with cerebral palsy have normal intelligence, which is masked by severe motor impairment. (With motorically handicapped individuals, accurate assessment of cognitive abilities can be difficult.) Most, however, have some degree of cognitive delay. Both groups require a program and environment that is optimal for learning. When devising a home- or center-based learning program, educators need to consider the limitations brought about by the child's motor and possible cognitive deficits; unrealistic expectations can be frustrating to both child and parents. Educators need to be especially patient with these children; studies show that they require a longer than usual period to respond to a request.

Most children with CP should avoid constant sitting, especially "W" sitting; instead they should assume different positions in order to prevent further tightening of muscles. Too, they need proper equipment to facilitate

eye-hand coordination, necessary for learning and for the performance of self-help skills.

Educators, who have regular contact with the child and family, can reinforce the advice of therapists and other service providers.

Positioning and Handling

Loretta Knutson Lough, L.P.T., M.A.

Positioning

Positioning is the process of placing a child with developmental disabilities in adapted or specially designed equipment to facilitate better posture and performance.

WHY POSITION A CHILD WITH DISABILITIES?

Standard, unadapted child care equipment often does not provide the necessary postural support for the individual with developmental disabilities. Lacking normal control of the body, the child may lean to one side, arch the back, or fall forward. Over extended periods, this may lead to joint contractures, scoliosis, hip dislocations, and other structural problems. Poor positioning can also cause pressure sores (decubitus ulcers).

Poorly Positioned Child ---
Note leaning to one side

Properly Positioned Child

The child who is properly positioned in adapted or specially designed equipment is more comfortable, may perform better, and has less chance of developing deformities. Proper positioning has advantages for the care taker as well, making the child easier to feed, transport, and otherwise manage.

EVALUATING THE CHILD'S POSITIONING NEEDS

Because body alignment can affect the whole spectrum of a child's learning and development, a team of professionals is usually involved in evaluating the child prior to ordering adaptive equipment. Typically, (1) physical and occupational therapists determine motor and adaptive function levels, (2) a nurse or physician evaluates general health status,

(3) a speech pathologist reviews language comprehension and speech motor skills; (4) a psychologist measures social and intellectual abilities, (5) a teacher determines educational goals; (6) an audiologist assesses hearing; and (7) a social worker identifies individual family needs—which *must* be considered if the equipment is to be put to proper use. When these evaluations are completed and reviewed by team members, the physical and occupational therapists are ready to measure the child and to select, order, and fit the appropriate equipment.

POSITIONING EQUIPMENT

Maintaining the best possible position for everyday functioning may include (1) adapting available childcare equipment, such as a stroller, carseat, highchair, potty chair, or classroom chair; (2) utilizing therapeutic equipment, such as a wheelchair; or (3) constructing equipment from original designs. While such equipment is usually for sitting, devices are also used for side lying, standing, and other positions Depending on the needs of the individual, adaptive equipment may have inserts for maintaining specific angles and inclines as well as head and neck supports and appropriate restraining straps

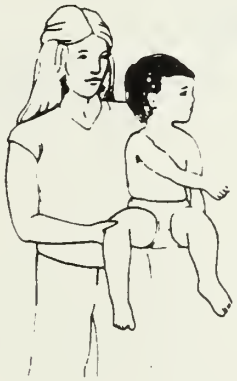
THE IMPORTANCE OF FOLLOW-UP

A child needs to build up skin or behavioral tolerance to the adapted equipment gradually A specific program for increasing tolerance is recommended. Once positioning is completed, the child should be reevaluated and the equipment examined at regular intervals. Changes in growth and motor abilities often require changes in the adaptive device

Handling

The child with a neuromuscular disorder must be picked up and carried correctly.

INCORRECT—Avoid lifting the child under the arms without supporting the legs. The child with high muscle tone (hypertonicity) may "scissor" the legs. The child with low muscle tone (hypotonicity) may slip through your hands.



CORRECT—Bend the child's legs before picking her up. Provide good support for both the trunk and legs. Encouraging rotation in the trunk is good particularly for the child with high muscle tone.

Gather the child with low muscle tone close to you to give him a feeling of stability.

For distances, you may want to have the child straddle your hip.

Name _____ Date _____

HOME INSTRUCTIONS

Side Sitting

Purpose

To help child learn to sit and balance on right or left side

Instructions

1. Place child in a side-sitting position (see Figure 1) on right or left side.
2. Provide toys to play with (see Figure 2).
3. Support as needed.

Desired Response

1. Child will maintain balance in side-sitting position.
2. Child will use one hand and two hands to play.

Undesired Response

1. Child will be unable to balance.
2. Child will use both hands for support.

Special Instructions

Figure 1

Figure 2

The exercises should be done only under the direction of a physical therapist.

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Name _____ Date _____

HOME INSTRUCTIONS

Pulling on Shirt—Prone on Lap

Purpose
To allow easier dressing without child becoming stiff

Instructions
1. Place child on stomach, lying on your lap (see Figure 1).
2. Hold the more involved arm above the elbow. Arm should be extended over head. Pull sleeve over arm (see Figure 2).
3. Slowly roll child over on back by pulling backward on "top" hip and supporting "lower" arm and trunk. Arms should be forward (see Figure 3).
4. Raise sleeveless arm above head. Pull sleeve over arms (see Figure 4).

Desired Response
Child will remain relaxed.

Undesired Response
Child will become stiff and dressing will be more difficult.

Special Instructions

Figure 1

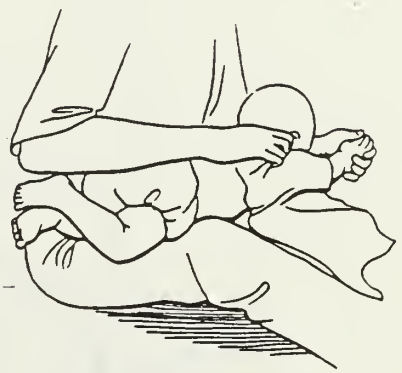

Figure 2

Figure 3

Figure 4

The exercises should be done only under the direction of a physical therapist.

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Name _____ Date _____

HOME INSTRUCTIONS

Playing in Sidelying

Purpose
To encourage child to play with hands in midline and to bring hands to mouth

Instructions
Place child on side as pictured below. Arms should be forward, and hips and knees should be bent. Head should be bent and may be supported for comfort. If necessary, assist child in bringing hands to midline to play and/or to the mouth.

Desired Response
Child will be able to bring hands to the midline and to the mouth.

Undesired Response
Neck, back, or legs will become stiff.

Special Instructions

The exercises should be done only under the direction of a physical therapist.

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Name _____ Date _____

HOME INSTRUCTIONS

Tilting on Ball Sideways and Back for Trunk (Control from Behind)

Purpose
To develop trunk control

Instructions
1. Place child sitting on a ball.
2. Support child by holding at the hips.
3. Gently and slowly roll the ball to the side and wait for a response (Figure 1).
4. Gently and slowly roll the ball backwards and wait for a response (Figure 2).

Desired Response
1. The trunk will adjust as the support is shifted.
2. The child will maintain head in an upright position.

Undesired Response
1. Child will fall toward the side or slump forward.
2. Child will arch backward and become stiff.
3. Child will use arms for support.

Special Instructions

Figure 1

Figure 2

The exercises should be done only under the direction of a physical therapist.

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Name _____ [' _____

HOME INSTRUCTIONS

Reaching on Stool

Purpose
To encourage weight shift and reaching

Instructions
1. Place child on a stool.
2. Provide a favorite toy to reach for just beyond child's grasp.
3. Support at hips or lower trunk if needed.

Desired Response
Child will be able to reach without falling.

Undesired Response
1. Child may fall to the side.
2. Child may bend down on one side of trunk.

Special Instructions

Figure 1

Reaching to the side

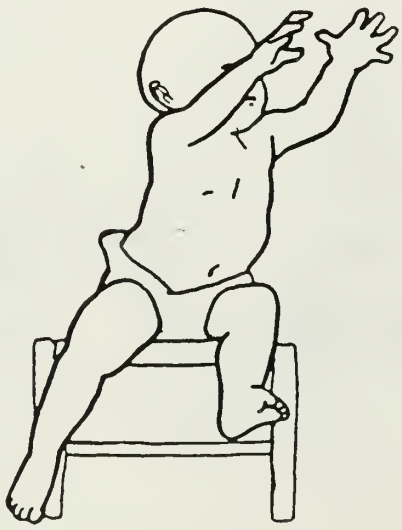

Figure 2

Reaching with both hands

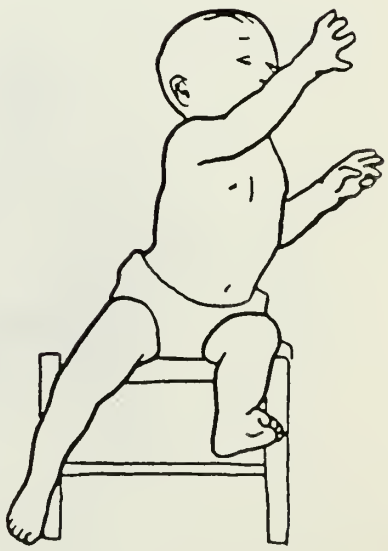

Figure 3

Reaching across the body

The exercises should be done only under the direction of a physical therapist.

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Name _____ Date _____

HOME INSTRUCTIONS

Playing Prone on Elbows

Purpose
To develop head and upper trunk control and ability to bear weight on elbows

Instructions
1. Place child on stomach with a roll under the chest.
2. Provide toys to play with and to look at.

Desired Response
1. The child will hold head up, but continue to look down at the toys (tuck the chin).
2. Child will support self on elbows.

Undesired Response
1. Child will lift head too far and be unable to look down.
2. Child will pull shoulders up or back.
3. Head or arms will pull down.

Special Instructions

The exercises should be done only under the direction of a physical therapist.

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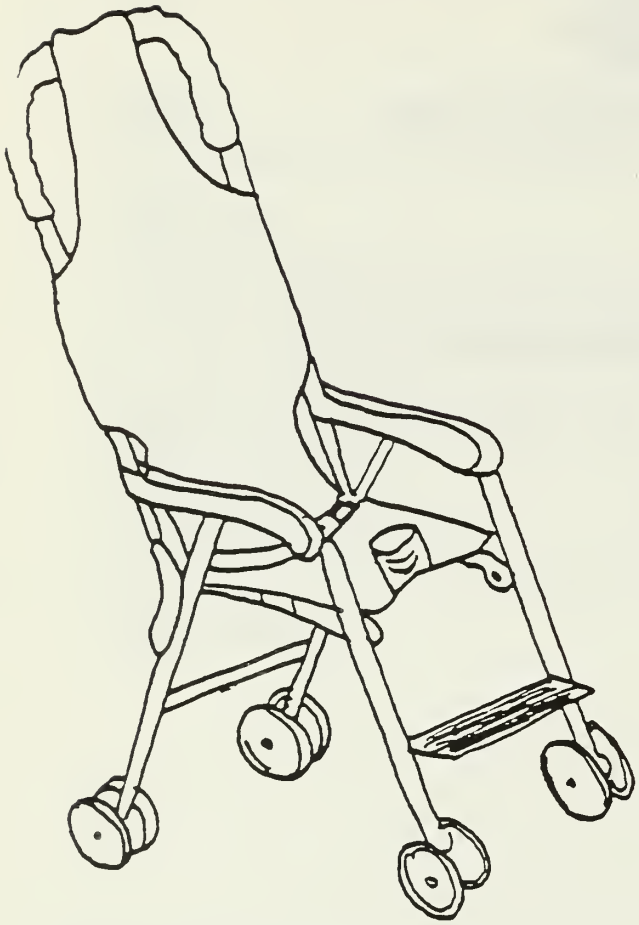
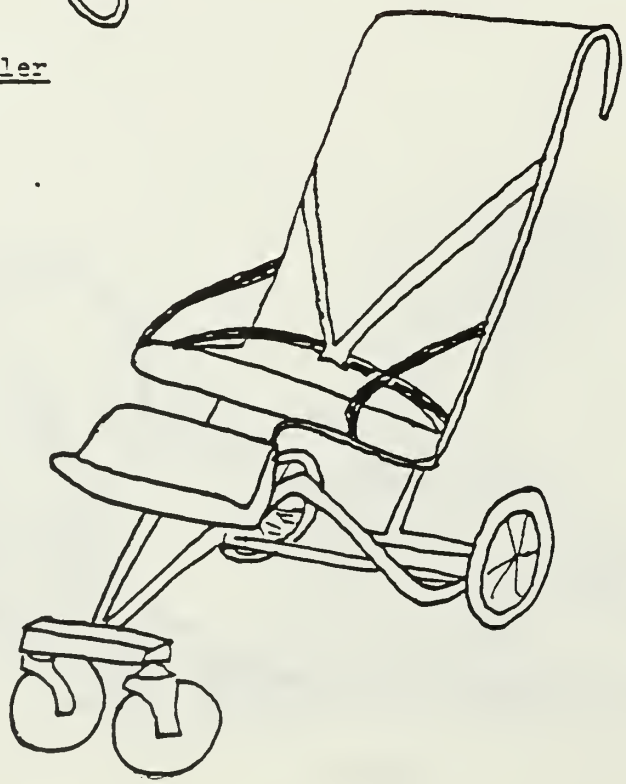
SPECIAL TRANSPORTATION CHAIRS



Pogon Buggy P.D.C., Inc.
36 Pleasant St.
Watertown, MA. 02172

Cosmopolitan Stroller
Equipment Shop
P.O. Box 33
Bedford, MA.



Transporter Chair
(These chairs can be purchased at the medical supply centers and there are quite a variety of them)

From Mass. Div. of Safety

DEVICES AVAILABLE FOR TRANSPORT OF CHILDREN WITH SPECIAL NEEDS

I. BRITAX CAR SEAT (EVENFLO SPECIAL CAR SEAT)

* ACCOMODATES CHILDREN 20-80 LBS. AND UP TO 60 INCHES TALL WITH MILD TO MODERATE DEFORMITIES
* USABLE FOR LARGER CHILDREN AND FOR A LONGER PERIOD OF TIME
* POSITIONING DEVICES ARE BUILT IN THEREFORE IT IS USABLE FOR DIFFERENT DEFORMITIES
* STROLLER ATTACHMENT IS AVAILABLE
* MEDICAID REIMBURSIBLE IN MASSACHUSETTS
* NEWER MODELS MAY BE EASIER TO USE, PADDING IS IMPROVED AND THEY WILL BE LESS EXPENSIVE

AVAILABLE FROM:
SHINN & ASSOCIATES
2109 LACDUMONT SUITE A1
P.O. BOX 552
HASLETTE, MICHIGAN 48840 (517) 339-1283
APPROXIMATE COST: $300 - $385 (CAR SEAT ONLY)
$500 - $600 (WITH STROLLER)

II. RUPERT E-Z-ON VEST

* DIFFERENT SIZES AVAILABLE FOR CHILDREN & ADULTS RANGING FROM 22" WAIST MEASUREMENT TO 43"
* DISTRIBUTES CRASH FORCES WELL. OTHER NETTING/STRAP VEST MAY NOT WORK AS WELL AS RUPERT VEST

* Provides some trunk support & more support than lap/ sholder belts

* It can be put on child and left on for transferring to another vehicle

* It is relatively inexpensive

* A modification for older children in body casts is available

* A tether anchor must be installed in each vehicle in which it is used

* Seat belts must also be used

AVAILABLE FROM:
E-Z-ON Products, Inc. of Florida
500 Commerce way West
Jupiter, Florida 33458 (305) 747-6920
Toll-free (800) 323-5598
Approximate cost: $55.00

III. TRAVEL CHAIRS

Convenient for general use as well as for a car safety seat

STC Travel Chair

This is the only one currently tested and approved for compliance with FMV #213 when used with appropriate restraint harness (supplied as standard accessory)

* Can be used as stroller/wheelchair as well as car safety seat

* Can be used to accomodate a range of sizes

* Only passes FMV #213 if the top tether is used. This is only available on the newer models and requires the installation of the tether anchor (must be ordered from company)

* Instructions for use are not clear (currently being modified)

* Some attachments lead to protruding hardware which may be dangerous for other passengers

* It is quite difficult to use and as a result many parents do not use it in the car as a safety device for transporting children

* It does not fit into all cars. TRY FOR FIT BEFORE PURCHASING

* Will not fit if the child's head is over the chair back (23"-58.4") when seated (corresponds to about 46"-117cm height)

* Van tie down option is not available from STC company but it may be compatible with the Q-straint and Aeroquip tie down systems.

AVAILABLE FROM:
STC
147 Eady Court
Elyria, Ohio 44035 (216) 365-7593
Approximate cost: $1500.00

Orthokinetic Chair

* Meets head excursion requirements for passengers up to 36 pounds. In order to meet FMV #213 chair must be anchored with lap/shoulder belt across passenger.

* Must install new seat belt or anchor belts on side of seat to hold chair in place

* Should be in front seat of vehicle, but fit is very difficult

* Back seat use not acceptable unless lap/shoulder belt is available

* Can be used in van or bus, with Q-straint **AND** lap shoulder belts

* Can be used with some level of safety if installed carefully and correctly according to manufacturers instructions

IV. WHEEL CHAIR TIE-DOWNS

Q-Straint

* Performs well in crashes tests

* Doesn't require special attachment points on the wheel chair

* Comes with lap belt

* Optional shoulder harness and chair brackets are available

* Relatively easy to use

* Hardware must be installed

AVAILABLE FROM:
Q'Straint
33 Highbridge Court
Cambridge, Ontario, Canada N1R 7L3 (591) 622-0000
Approximate cost: $370.00

NOTE: Other tie-down devices are available from Aeroquip and CCI/Masterlok

V. VANS

Target Industries (Modification of Dodge Caravan)

* Customized Modifications

* Convenient to use

* Smaller and less expensive than full sized vans

* Uses a tie down system

* Shoulder harness available only as an option

AVAILABLE FROM:
Target Industries
P.O. Box 657
6 Thompson Rd.
East Windsor, CT. 06088 (203) 627-5191
(or from local dodge dealer)
Approximate cost: $6-9,000 over base price of van ($10-12,000)
Total Cost: $16,000 - $21,000

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH
SCHOOL HEALTH SERVICES PROGRAM
80 Boylston Street, Suite 742, Boston, MA 02116

SCHOOL HEALTH FORMS

ORDER FOR SCHOOL YEAR 1983-84

(INCLUDE SPRING AND SUMMER 1984 REGISTRATION NEEDS)

_____
(NAME OF TOWN, SCHOOL SYSTEM OR PROGRAM)

TYPE OF AGENCY (check one)

School Dept: ☐
Board of Health: ☐
Private School: ☐
Day Care/Pre-school: ☐
Other: ☐

DELIVERY ADDRESS (include street or location, not just box number):

_____

_____

_____

CONTACT PERSON: _____

PHONE: _____

_____ SAMPLE SET OF ALL FORMS

NUMBER OF COPIES NEEDED	RECORD FORMS
_____ PH-M-1	SCHOOL HEALTH RECORD CARD (Revised 1983)
_____ PH-M-1A	SCHOOL HEALTH RECORD CARD (Continuation Sheet)
_____ PH-M-2	INTERVAL HEALTH HISTORY (parent)
_____ PH-M-14	NOTICE TO PARENT OR GUARDIAN
_____ PH-M-18	PRIVATE PHYSICIAN'S REPORT (Initial Evaluation) (revised 1983)
_____ PH-M-18A (Rev. 1983)	PRIVATE PHYSICIAN'S REPORT (Subsequent Evaluation Only)
_____ PH-M-31	INDIVIDUAL AUDIOGRAM CARDS - BLUE
_____ PH-M-50B	PERCENTILE CHART FOR PHYSICAL MEASUREMENTS OF BOYS
_____ PH-M-50G	PERCENTILE CHART FOR PHYSICAL MEASUREMENTS OF GIRLS

WORKSHEETS

_____ PH-M-44	VISION AND HEARING WORKSHEET (22 children per sheet)
_____ PH-M-54	PRESCHOOL VISION & HEARING WORKSHEET (24 per sheet)
_____ PH-M-64	POSTURAL SCREENING WORKSHEET (24 per sheet)

PLEASE RETURN THIS FORM PROMPTLY TO THE ADDRESS SHOWN ABOVE.

PLEASE! CIRCULATE TO ALL BUILDINGS OR PROGRAMS IN YOUR SYSTEM AND SUBMIT ONE CONSOLIDATED ORDER PER YEAR. THANK YOU!

CONVENTIONAL DEVICES FOR SPECIAL NEEDS

I. FRAIL CHILDREN

* THE FORD TOT-GUARD IS GOOD FOR FRAIL CHILDREN AS IT DISTRIBUTES FRONTAL CRASH FORCES OVER THE WIDE AREA OF THE SHIELD, TOT-GUARD HAS THE LARGEST PROTECTIVE SHIELD CURRENTLY ON THE MARKET: AVAILABLE ONLY FROM FORD MOTOR COMPANY

* CAN BE LEFT BELTED IN PLACE AND DOESN'T REQUIRE HARNESSING

* A DISADVANTAGE IS THAT AN ACTIVE CHILD CAN CLIMB OUT OF THE TOT-GUARD. THIS SEAT IS RATED FOR CHILDREN UP TO 50 LBS.

* IN GENERAL, RESTRICTIVE SEATS (THOSE WITH SHIELDS AND/OR ADDITIONAL HARNESSES) ARE BEST

II. CONGENITAL HIP DISLOCATION REQUIRING HIP SPICA CASTS

* INFANTS IN A HIP SPICA CAST CAN BE TRANSPORTED IN THE CENTURY 100, 300 OR STROLLEE 612 WHICH CAN BE MODIFIED FOR PROPER FIT WITHOUT DIMINISHING ITS PERFORMANCE

III. LONG LEG OR BROOMSTICK CAST

* THESE ARE BEST ACCOMMODATED IN A SHALLOW SEAT SUCH AS THE COSCO-PETERSON SAFE-N-EASY OR A BOOSTER SEAT WITHOUT SIDES (SUCH AS THE STROLLEE 601). THESE MUST BE USED WITH AN INSTALLED TORSO HARNESS WHICH COMES WITH THE SEAT. THE STROLLEE 601, THOUGH STILL SOMEWHAT AVAILABLE, IS NOW DISCONTINUED.

IV. CHILDREN WITH BEHAVIOR PROBLEMS

* The Rupert Vest is the most suitable device for restraining children with behavior problems

* The Bobby-Mac Delux or Champion models are also relatively escape proof and therefore advantageous. The champion model however, is now discontinued

V. CHILDREN REQUIRING SPECIAL FACIAL PROTECTION (e.g. RECENT SURGERY, EYEGLASSES)

* Use seats with five point harnesses rather than those with an armrest in front

VI. PIERRE-ROBIN SYNDROME OR GASTRO ESOPHAGEAL REFLUX

* Children requiring an upright or upright/prone position Pierre-Robin Syndrome (small jaw with cleft palate) or severe gastroesophageal reflux (spitting with choking)

* These children can be accommodated in the Dyn-o-mite infant car seat if they are placed facing the seat back and positioned with a 2" velcro strap running over the head and back through the slots in the seat

VII. INFANTS UNDER 20 lbs. WHO CANNOT SIT UP FOR ANY REASON

* The Romer Swinger (evenflo swinger car bed) may be used for infants under 20 lbs. who cannot sit up. This European product is crash tested but its incompatibility with American seat belt hardware has previously prevented its use in this country.

* It is currently available and federally approved for use with special hardware for conversion to the American seat belt system

* May be used for premature infants who cannot ride in conventional car seat

AVAILABLE FROM:
Shinn & Associates
P.O. Box 552
Haslett, Michigan 48880 (517) 339-1283
Approximate Cost: $200

VIII. OLDER CHILD IN BODY CAST

These children can be restrained in a prone position wearing a Rupert vest. An additional belt must be added for attachment to a seat belt which is strapped around the lower extremity. Additional belts and instructions are available from Rupert Industries. (see E-Z on Vest)

VI. PREMATURE INFANTS (USUALLY DISCHARGED FROM HOSPITAL AT 4½ TO 5 LBS.)

* Infants under five pounds may not fit well or safely in many of the car seats which meet Federal standards for infant transport

* Short seat back to crotch strap and shoulder strap to seat bottom distances are needed. Desirable measurements would be under 5½" (14cm.) and 11" (28cm.) respectively

* A plastic retainer clip is necessary and keeps the shoulder strap together. Use of a blanket roll on each side of the child will help position the head and prevent slouch.

THESE SHOULD NOT BE USED BETWEEN THE CHILD AND THE BACK OF THE SEAT BUT MAY BE USED BETWEEN THE CHILD AND THE HARNESS AND ON THE SIDE OF THE SEAT.

* CAR SEATS WITH SHIELDS SHOULD NOT BE USED. IN MOST CASES, THEY MAKE CONTACT WITH THE INFANT'S FACE.

SEATS MEETING ABOVE CRITERIA:

INFANT ONLY SEATS

* COSCO FIRST RIDE
* DYN-O-MITE

CONVERTIBLE SEATS

* CENTURY 100 OR 300
* TEDDY TOT ASTROSEAT

* ROMER SWINGER (EVENFLO SWINGER CAR BED) IS A GOOD CHOICE FOR PREMATURE INFANTS UNDER 5 LBS. UNTIL THEY CAN RIDE SAFELY IN A CONVENTIONAL SEAT.

SAFE TRANSPORTATION FOR HANDICAPPED CHILDREN

A joint project of the Massachusetts Chapter of the American Academy of Pediatrics, Accident Prevention Committee and the Massachusetts Passenger Safety Program, Department of Public Health.

Massachusetts Passenger Safety Program
Massachusetts Department of Public Health
Division of Family Health Services
150 Tremont Street
Boston, MA 02111

(617) 727-1246
1-800-CAR-SAFE outside the Boston area

Massachusetts
P.S.
Passenger ■ Safety
Program

A Family Shopping Guide To:

Infant/Child Safety Seats

of the seats on this list meet Federal Motor Vehicle Safety Standard 213

American Academy of Pediatrics

January 1986

	NAME OF SEAT	MANUFACTURER/ DISTRIBUTOR	COMMENTS	MANUFACTURER'S S RETAIL PRICE
INFANT SAFETY SEATS Birth to approximately 20 Pounds Rear Facing Only	Century 570 Infant Car Seat	Century	2 Position Harness, Push Button Release	$25.30
	Century 580 Infant Car Seat	Century	2 Position Harness, Removable Rocker	$45.55
	Cuddle Shuttle	Collier-Keyworth	1 Position Harness	$41.00
	Dyn-O-Mite	Evenflo	2 Position Harness	$28.00
	First Ride	Cosco	1 Position Harness	$28.00
	Infant Carrier	Ford	1 Position Harness	$40.00
	Infant Love Seat	Century	1 Position Harness	$30/40
	Rock N' Ride	Kolcraft	3 Position Harness	$25/35
	Snug Seat	Graco	3 Position Harness	$40.60
CONVERTIBLE SAFETY SEATS Birth to approximately 40 Pounds Infants Rear Facing Toddlers Forward Facing	Bobby-Mac Deluxe II	Evenflo	2 Position Harness/Shield	$50.00
	CK Classic	Collier-Keyworth	Harness/Shoulder straps connect to partial shield	$60.00
	Century 100	Century	Harness	$45/55
	Century 200	Century	Harness/Body Pad	$55.65
	Century 300	Century	Harness/Shield	$65/75
	Century 400XL	Century	Harness/Shield	$80/100
	Concor V	Aprica	Harness/Body Pad	$129.00
	Cosco Commuter	Cosco	2 Position Harness/Self Adjusting Shield	$62.00
	Cosco Safe-T-Seat	Cosco	2 Position Harness	$55.00
	Cosco Safe & Snug	Cosco	2 Position Harness adjusts with shield	$44.00
	Cosco Safe & Easy	Cosco	2 Position Harness	$40.00
	Fisher-Price	Fisher-Price	Harness/Body Pad/Shoulder straps connect to partial shield	$75.80
	Formula 1	Collier-Keyworth	Harness/Shoulder straps connect to partial shield	$80.00
	Gerry Guardian	Gerry	Harness/Full Shield/Armrest	$80.00
	GT1000	Graco	Harness	$70.90
	Hi Rider XL 7	Kolcraft	Adjustable Shield/Armrest/Harness	$50/65
	One Step	Evenflo	2 Position Harness/Partial Adjustable Shield	$50.00
	Plush Wee Care 614	Strolee	Harness	$49/69
	Plush Wee Care 620	Strolee	Harness/Removable Armrest	$65/85
	Pride-Ride 825 & 827	Pride-Trimble	Harness	$50.00
	Pride-Ride 830-1	Pride-Trimble	Harness/Armrest	$85.00
	Pride-Ride 832	Pride-Trimble	Harness/Armrest	$95.00
	Pride-Ride 835 & 837	Pride-Trimble	Harness/Armrest	$70.00
	Roundtripper	Collier-Keyworth	Harness	$49.00
	Sprint	Collier-Keyworth	Harness	$65.00
	STE1000	Century	Harness	$50/65
	STE2000	Century	Harness/Body Pad	$65/80
	Travel Tot	Welsh	Harness/Partial Shield/Armrest	$63.29
	Wee Care 609	Strolee	Harness	$35/55
	Wee Care 610	Strolee	Harness/Removable Armrest	$39/59
	Wee Care 618	Strolee	Harness/Removable Armrest	$49/69
	Wonda-Chair 810	Babyhood Industries	Harness	$79.95
TODDLER SEATS 20-40 Pounds Forward Facing	Bobob 2	Z.B. Sales, Inc	5 Point Harness/Armrest	$129.00
	SafeGuard	Evenflo	2 Position/5 Point Harness/Partial adjustable shield	$30.00
BOOSTER SEATS 30-60 Pounds Forward Facing	Click-n-Go 890	Pride-Trimble	3 Position Shield	$23.00
	Click-n-Go 891	Pride-Trimble	3 Position Shield	$28.00
	Co-Pilot II	Collier-Keyworth	Full Shield	$22.50
	Commander 4810	Century	Pivoting Growth Shield	$20/30
	Cosco Explorer	Cosco	Adjustable Shield	$23.00
	Evenflo Booster Car Seat	Evenflo	Shield	$41.00
	Flip N' Go II	Kolcraft	Adjustable Shield	$20/25
	Quick Click 605 Booster	Strolee	Full Shield	$25/45
	Quik-Step Tot-Rider	Kolcraft	T-Shield	$50/65
	Tot Guard	Ford	Full Adjustable Shield	$65.00
	Voyager	Collier-Keyworth	Full Shield	$40.00
	Wings	Evenflo	Partial Adjustable Shield	$25.00
OTHER	Britax Car Seat	Evenflo	Suitable for the disabled child up to 80 lbs. or 60"	$385.00
	E-Z-On Vest	E-Z-On Products	4 Models available/Suitable for persons up to 164 lbs	$49.25
	Evenflo 7 Year Car Seat	Evenflo	Convert. Seat & Booster/2 Position Harness/Partial Adjust. Shield	$100.00

Supported by an educational grant from Evenflo Juvenile Furniture Co.

American Academy of Pediatrics
Division of Public Education
141 Northwest Point Blvd.
P.O. Box 927
Elk Grove Village, IL 60007
ER6006

MAKE EVERY RIDE A SAFE RIDE

Protecting Your Child's Health

We all want happy and healthy children That takes thought and effort every day

Most of us have learned to be very careful in our own homes We lock away harmful substances. We keep hot irons and pots and pans out of reach. We cover electrical outlets and sharp table corners. The water heater is set no higher than 130 degrees. And you can think of many other things that you do to protect your children at home.

Sometimes, however, we leave our caution at the front door or in the garage!

In the rush of transporting ourselves and our children from place to place in this busy world, many of us neglect to protect our children from the **number one preventable cause of death** for young children: **injuries suffered while riding in cars.**

Each year approximately 42,000 children under the age of five years are reported as injured and 600 children die because they are not protected by child car safety seats or seat belts.

What Can I Do to Protect My Child?

Infants and young children **always** should ride in car safety seats. A safety seat will hold your child securely in the car and help absorb the forces of even violent crashes. Remember, it is, also, the law in all 50 states that children ride in safety seats. Obey the law and protect your child.

Which Safety Seat is the Best?

All the seats on this list are safe. The best one for your child is the one you will use according to the manufacturer's directions every time your child travels

Isn't My Baby Safe Being Held Tightly In My Arms?

No. When traveling in a car, your arms are the most dangerous place for your baby. This is called "the child crusher position." In a low speed, 30-mph crash, even a tiny 10-lb. infant would be ripped from your arms with a force of almost 300 lbs. That's like falling from a three-story building. If you are not using your seat belts, your child would be crushed between your body and the windshield and dash

How Can I Best Protect My Infant?

Beginning with the first ride home from the hospital, all infants should ride in a semi-reclined, **rear-facing** car safety seat. It must be anchored to the vehicle with a seat belt, and the harness must be fastened. "Car beds" and flimsy household infant carriers are not designed to protect an infant in a car.

What Does A Toddler Or Pre-Schooler Need?

All children who can sit up alone or who weigh from 20-60 lbs. should be buckled into a **forward-facing** car safety seat. It must be anchored with a seat belt and with the top anchor strap, if one is provided with the seat. Make sure the harness or protective shield is in place.

What If My Child Must Ride In A Car Without A Safety Seat?

If a car seat is not available for a toddler the regular seat belt in the back seat of the car should be used. This is safer than riding unrestrained. The seat belt must be snug over the hip/thigh bones . not over the belly

Do Airlines Allow The Use of Safety Seats?

Check with your airline before you make reservations, as not all airlines allow safety seats. All seats made after February 1985 are labeled for aircraft use. If your safety seat was made between January 1, 1981 and February 26, 1985, it must have an F A A approved sticker before you board. Seats made before January 1, 1981 are not allowed by the airlines.

Anything Else I Should Know?

- If money is a problem, see if service organizations or hospitals in town are renting or loaning car safety seats.
- Be sure that you read the directions for use of the car seat. Use it exactly as recommended, or your child will not be as safe as possible.
- Whenever possible, put children in the back seat. It's safer than in the front seat.
- Everyone in the car must buckle up. An unrestrained child or adult can be thrown into other passengers and cause serious or even fatal injuries.

Improving Your Child's Behavior

When you take your children for a drive in the car, have you ever been aggravated or distracted by their behavior? Do they climb around the seat, fight, and pull at you or the steering wheel? If you have to answer "yes," then your children are not buckled up.

Buckled Up = Better Behavior

Researchers at the University of Kansas Medical School have proved that "buckled up equals better behavior." In several studies they observed children riding in cars with their parents. When not buckled up, the children squirmed around on the seats, stood up, complained, fought, and pulled at the steering wheel When buckled into car safety seats, however, there were 95% fewer incidents of bad behavior.

Why do children behave better when buckled up?

- They feel secure In sudden stops and swerves, they are held snugly and comfortably in place
- Most car safety seats lift children high enough to see out the window They want to watch the world go by, too!
- Children are less likely to feel car sick and more likely to fall asleep.

Buckled Up = Fewer Accidents

A recent study in North Carolina has offered proof that hundreds of crashes in that state each year are caused when unrestrained child passengers distract their drivers. Think for a moment: how much attention do you pay to your driving when your child falls off the seat, hangs out the window, pulls your hair, or tries to open the door?

With your children buckled up, you can concentrate on your driving without having to worry about their being hurt. You also will be calmer and more relaxed . . . as will your children . . . when you arrive at your destination.

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THE CARDIO-RESPIRATORY SYSTEM

Objectives

After completing this unit, participants will:

1. Describe the anatomy and function of the circulatory and respiratory systems.
2. Discuss two of the primary cardiac disorders of childhood.
3. Explain the causes, transmission modes and management of children with AIDS.
4. Outline the components of respiratory therapy.
5. Explain the procedure for administering postural drainage therapy.

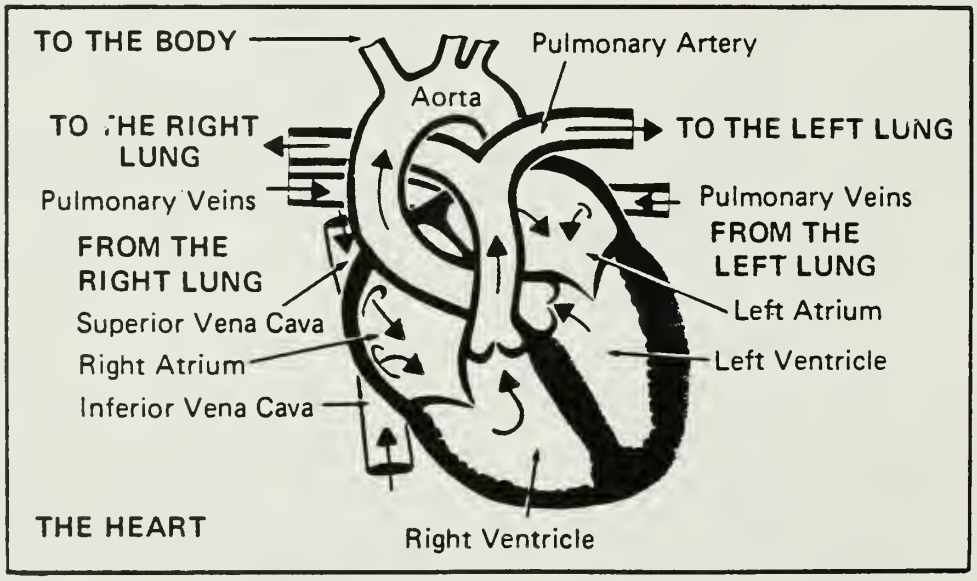
The Circulatory System

ANATOMY

Organs: heart, blood, blood vessels, spleen, lymph, lymph nodes and lymph vessels

Function: carries food, oxygen and water to body cells: removes waste from cells; includes the immune system which protects the body from infections

The heart pumps the blood through a series of chambers and large vessels and controls the flow of blood by means of valves located between the chambers.



DISORDERS

Birth Defects

- Problems occur because the vessels and/or the heart have congenital defects, malformations which arise during the first few weeks of fetal development.

(continued)

- abnormal openings may be present between the chambers of the heart
- vessels leading to or from the heart may be arranged the wrong way
- vessels may be too small to carry enough blood

Diagnostic Tests

- chest X-ray
- blood tests
- electrocardiography (EKG)
- fluoroscopy: a test in which a picture of the heart, like a TV screen image, is taken through the chest wall to show the outline of the heart and its pumping action.
- cardiac catheterization: a procedure performed by inserting a thin plastic tube into an arm or leg vein and advancing it to the heart. Its position is seen by watching through a fluoroscope. Malformations can be defined in this way.
- angiography: the injection of dye through the cardiac catheter so that X-rays of the heart can be taken as the blood passes through the chambers and major vessels.
- echocardiography: recording the position and motion of the heart borders and valves by reflected echoes of ultrasonic waves transmitted through the chest wall. This procedure is frequently used, reducing the need for cardiac catheterization, a more invasive diagnostic procedure.

Management and care

Open or closed heart surgery which may also require:

- ventilation accompanying the oxygen therapy
- medication: primarily digitalis and diuretics for cardiac failure
- transfusion

(continued)

- nutritional assessment and treatment
- antibiotics for secondary infections
- allowing the child to self-regulate activity

Rheumatic Carditis

Three out of every hundred respiratory strep infections, such as strep throat, result in rheumatic fever if untreated. Therefore, the way to prevent rheumatic carditis is to treat a strep infection before it develops into rheumatic fever. One half of all strep infections have no symptoms, while the other half produce the familiar signs of a cold -- fever, headache, sore throat and swollen lymph nodes in the angle of the jaw. Positive diagnosis is made by throat culture.

Both acute and recurrent attacks of rheumatic carditis are triggered by streptococcal infections of the upper respiratory tract. Despite a decline in the severity and prevalence of rheumatic fever in recent years, rheumatic carditis is still the leading form of acquired heart disease in children. It occurs in approximately 40% of the children during the first attack of rheumatic fever. Although one third of children with this disorder recover completely with no residual heart damage, in other instances damage results to the valves which control the flow of blood through the heart chambers.

Children who have had rheumatic fever are prone to recurrent attacks; each one has a chance of causing permanent heart damage.

(continued)

Prevention

- Diligent medical management of suspected strep infections
- Continuous prophylactic (preventive) antibiotic therapy for children with a history of rheumatic fever or clear evidence of rheumatic carditis to prevent recurrences.
- Examination of family contacts through throat cultures

Management and care

- Complete eradication of streptococcus infections by prolonged treatment with antibiotics
- Strict bed rest
- Digitalis for heart failure
- Corticosteroids for joint disease, which may accompany carditis

Pediatric AIDS

See supplementary readings.

The Respiratory System

ANATOMY

Organs: nose, pharynx, trachea, bronchi, bronchioles, alveoli

Function: as oxygen is inhaled and diffuses into the capillaries, carbon dioxide comes into the alveoli and is exhaled

Factors to consider when discussing respiratory diseases of childhood are:

- Infants are obligatory nose breathers.
- The alveoli continue to mature and develop with age.
- The airway size influences the ability to handle mucus.
- Breathing requires effort and energy.

DISORDERS

Respiratory Distress Syndrome (RDS) or Hyaline Membrane Disease

Premature infants are susceptible to a variety of disorders associated with insufficient development of key organ systems. The major cause of death in the newborn is RDS.

Cause

Although the cause is unknown, two mechanisms seem to be central to its development:

1. A deficiency in surfactin, the substance which lines the alveoli and allows the lungs to expand easily by reducing surface tension. A major component of surfactin is lecithin, which is lacking in premature babies.

(continued)

2. Intrauterine or neonatal hypoxia (lack of oxygen) ultimately leads to a lack of blood supply to the cells that produce surfactin and/or lecithin.

Prevention

- Prevention of prematurity
- Avoidance of unnecessary caesarean sections
- Careful management of diabetic mothers
- Amniocentesis to aid in predicting RDS when:
    - labor occurs at less than 37 weeks gestation
    - caesarean delivery is planned because of difference in the calculated age of the fetus and clinical impression
    - the mother has high blood pressure
    - RH sensitivity is present
- Corticosteroids which speed fetal lung development may be administered to the pregnant woman

Management and care

- Anticipation of the risk for developing RDS
- Early recognition, resuscitation and transfer to an Intensive Care Nursery (ICN)
- Prevention of chilling to reduce the need for oxygen
- Careful monitoring of oxygen administration with the provision of pressure to allow the alveoli to expand
- Assisted ventilation by intermittent use of mask and bag resuscitator may be necessary for infants who cannot maintain respiration without assistance, have persistent cyanosis or whose carbon dioxide tension is too high

Broncho-pulmonary dysplasia (BPD) or Bubbly-Lung Syndrome

This is a syndrome of premature infants, usually of less than 32 weeks gestation and with birth weight below 1500 grams. This disorder has been seen in infants who developed pulmonary disease following respiratory therapy and oxygen for hyaline membrane disease. It is characterized by irregular breathing, irregular heart rate, retractions and cyanosis (bluish color caused by lack of oxygen) during the first month of life. The mortality rate for these infants is similar to that of RDS, 25%.

Treatment

- Oxygen for cyanosis, which may need to be administered for several months
- Digitalis and diuretics (water pills) for cardiac failure
- Assisted ventilation if necessary

Asthma

Asthma, the most common chronic disease in children, is a disorder of the lung passages characterized by chronic or episodic attacks of wheezing, coughing, and shortness of breath. These attacks occur unexpectedly and may be frightening to the child as well as to those around him or her.

The small bronchial tubes become obstructed by:

- constriction of muscles surrounding the tubes
- swelling of the mucus lining of the tubes
- formation of thick plugs of mucus within the tubes
- or a combination of these conditions

(continued)

The obstruction of the tubes allows air to be breathed in but the child has difficulty in exhaling all the air. This causes the lungs to be overinflated, with the child straining to force air in and out of the lungs.

Causes

- Allergies to one or more substances, such as smoke, dust, food or ingredients in cosmetics or dyes. These substances combine with antibodies to produce histamine, which causes the symptoms of allergy.
- Intrinsic sensitivity of the bronchioles to a stimulus such as overexertion, a cold, sore throat or emotional excitement.

Management and care

- Administration of medication to dilate the bronchioles and/or loosen the mucus plugs
- Inhalation therapy and breathing exercises
- Avoiding factors that may trigger attacks such as:
    - exposure to people who have colds or flu
    - strenuous exercise
    - contact with allergens
    - exposure to smoke
    - overreaction of child or parents to the experience of an asthma attack
- Physical fitness plan

Cystic fibrosis

Cystic fibrosis (CF) is an inherited disease which is first noticed in babies because of lung and/or digestive problems. Cystic fibrosis causes the mucus-secreting glands to produce abnormally thick mucus. This mucus blocks the breathing passages (bronchi), resulting in a chronic cough and episodes of respiratory infections. Thick mucus may also block the ducts of the pancreas, which supplies enzymes needed to digest food. When the enzymes do not reach the intestine, food is only partly digested and absorbed, thereby reducing growth and weight gain.

Management and care

- Oral medications
    1. Antibiotics
    2. Vitamins
    3. Essential fatty acids
    4. Bronchodilators
    5. Pancreatic enzymes
- Inhaled medications
    1. Bronchodilators
    2. Other inhalation medication
- Physiotherapy
    1. Postural drainage
    2. Percussion
    3. Breathing exercises
    4. Exercise

(continued)

Potential Respiratory System Complications

- Atelectasis (collapse of part of the lung)
- Pneumonia
- Pneumothorax: a condition in which air leaks into the space between the lung and the chest wall
- Bronchiectasis: a condition in which the bronchial wall becomes rough and the tubes become grape-like instead of straight
- Hemoptysis (coughing up blood)
- Nasal polyps (inflammatory pouches of the nasal cavity or sinuses)

RESPIRATORY THERAPY

Components

1. Conditioning and moistening the airways and secretions by medication, fluid intake and breathing moist air
   - Humidifier
   - Nebulizer
     - ultrasonic
     - small volume
     - practical management
     - medication
2. Breathing retraining
   - Pursed lip breathing
   - Diaphragmatic breathing
   - Controlled cough technique
3. Postural drainage, percussion and vibration
   - Positioning during postural drainage
   - Percussion technique
4. Suctioning

(continued)

5. Delivery of oxygen and humidification

    - Nasal cannula

    - Mask

    - Tracheostomy mask or T tube

    - Tent

6. Aid to ventilation

    Ventilation is the movement of air into and out of the lungs

    - Intermittent positive pressure breathing (IPPB)

HANDS-ON TREATMENTS

1. Introduction

2. Apnea monitor

3. Delivery of oxygen and humidification

    - mask

    - cannula

    - tent

4. Aerosol delivery

    - hand-held

    - machine-delivered

5. Pulmonary hygiene

    - positioning/postural drainage

    - percussion and vibration

    - mucus clearance

        - cough, huff

        - tracheal stimulation

        - suctioning

    - breathing techniques

BIBLIOGRAPHY

1. Blackman, James A. (Ed.), Medical Aspects of Developmental Disabilities in Children Birth to Three. Iowa City: University of Iowa, 1983.

2. Jones, Monica Loose, Home Care for the Chronically Ill or Disabled Child. New York: Harper and Row, 1981.

3. Staff Manual for Teaching Patients about Obstructive Pulmonary Diseases. Chicago: American Hospital Association, 1979.

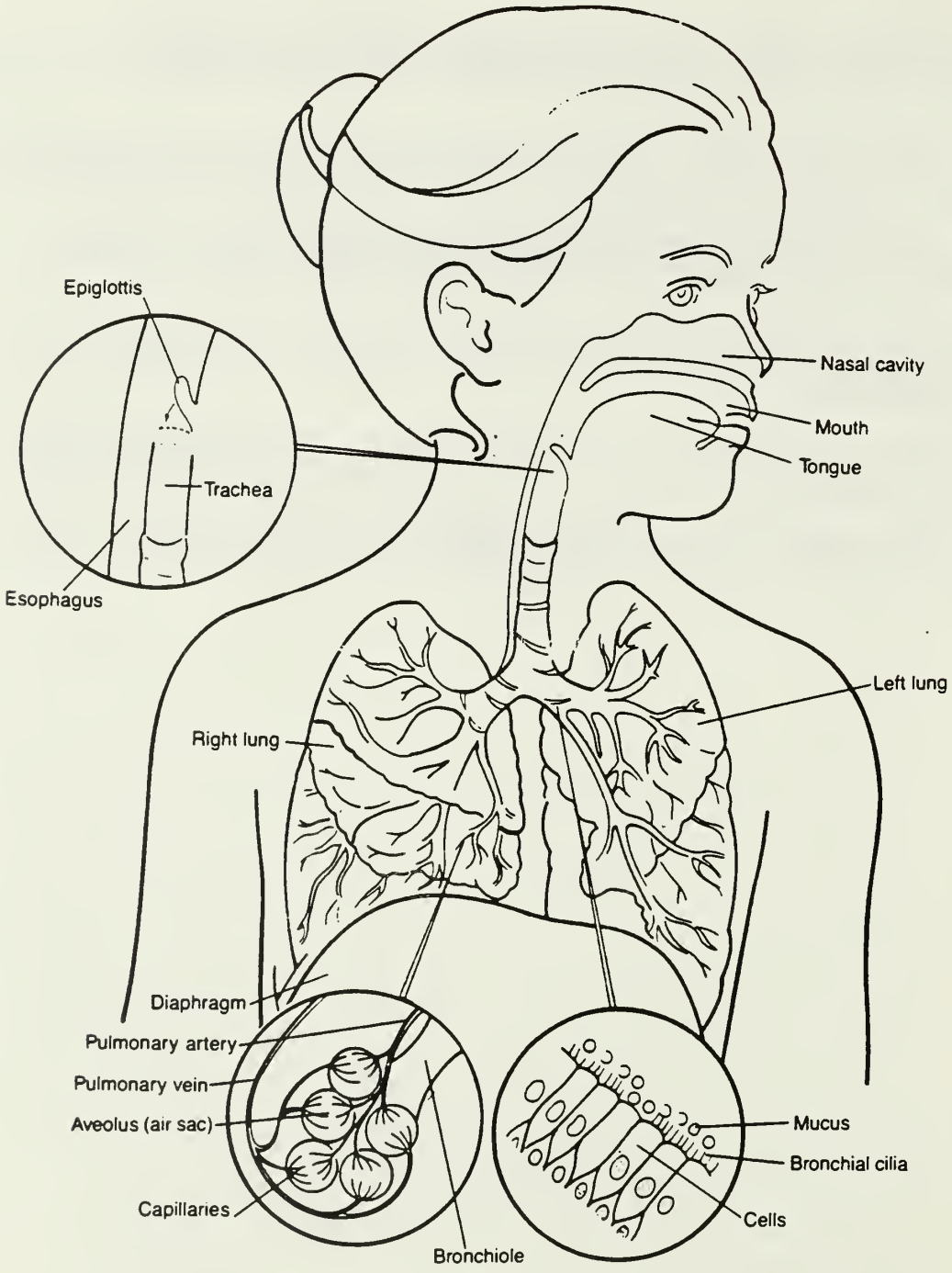
4. Patterson, Paul R; Denning, Carolyn and Kulcher, Austin H., (Eds.) Psychosocial Aspects of Cystic Fibrosis. New York: The Foundation of Thanology, 1973.

5. Shapter, Elizabeth (Ed.), Cystic Fibrosis: A Teaching Manual for Parents and Patients. Toronto: The Hospital for Sick Children, 1984.

6. Zucker, Elana, (Ed.), Being a Homemaker Home Health Aide. Bowie, Maryland: The Robert J. Brady Co., 1982.

From:

Jones, Monica Loose, Home Care for the Chronically Ill or Disabled Child, New York:Harper and Row, 1981.



The respiratory system.

From:

Blackman, James A., M.D., (Ed.) Medical Aspects of Developmental Disabilities in Children Birth to Three. Iowa City: The Univercity of Iowa, 1983

Congenital Heart Disease

James A. Blackman, M.D.

DESCRIPTION

Congenital heart disease (CHD) includes cardiovascular malformations which are present and usually evident at the time of birth, but which may not be recognized until months or even years later.

The body is dependent upon the heart to pump oxygen and nutrients to all its tissues; therefore, physiologic, anatomic, or electrical defects are debilitating and potentially life-threatening. The more common heart defects include coarctation of the aorta, patent ductus arteriosus (PDA), atrial septal defect (ASD), ventricular septal defect (VSD), tetralogy of Fallot (TOF), and transposition of the great arteries (TGA):

Coarctation of the aorta

A narrowing of the aorta causes the left ventricle to pump harder, raising the blood pressure above the constricted part and lowering it in the blood vessels below.

Patent ductus arteriosus

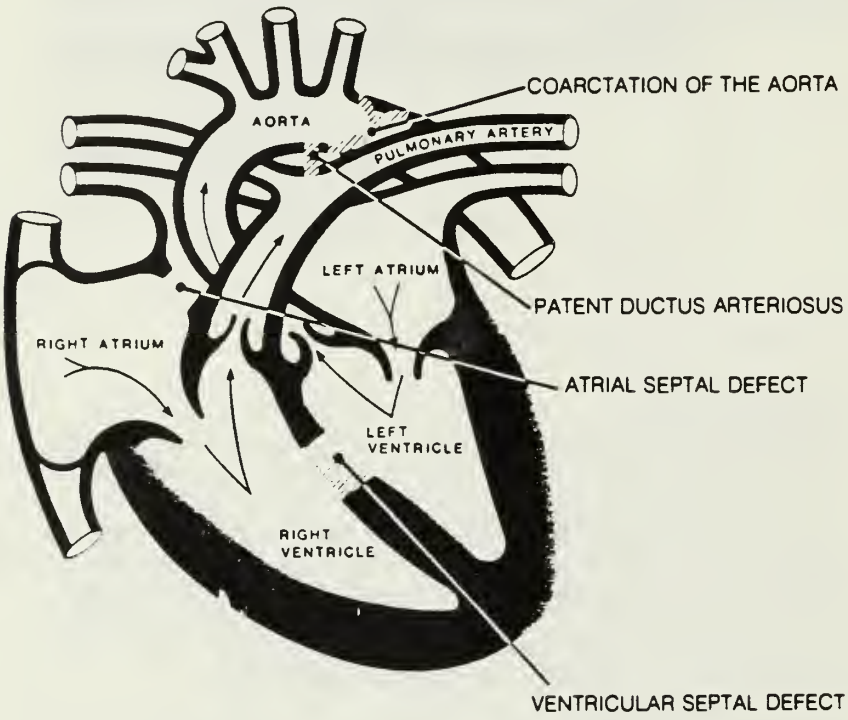
The duct used to bypass the lungs in the fetus remains open after birth. Oxygenated blood from the left side of the heart flows across the duct, back into the pulmonary artery; this makes the left ventricle work harder and floods the lungs.

Atrial septal defect

Blood leaks through a hole in the wall from the left to the right side, enlarging the right atrium and ventricle as well as the pulmonary artery.

Ventricular septal defect

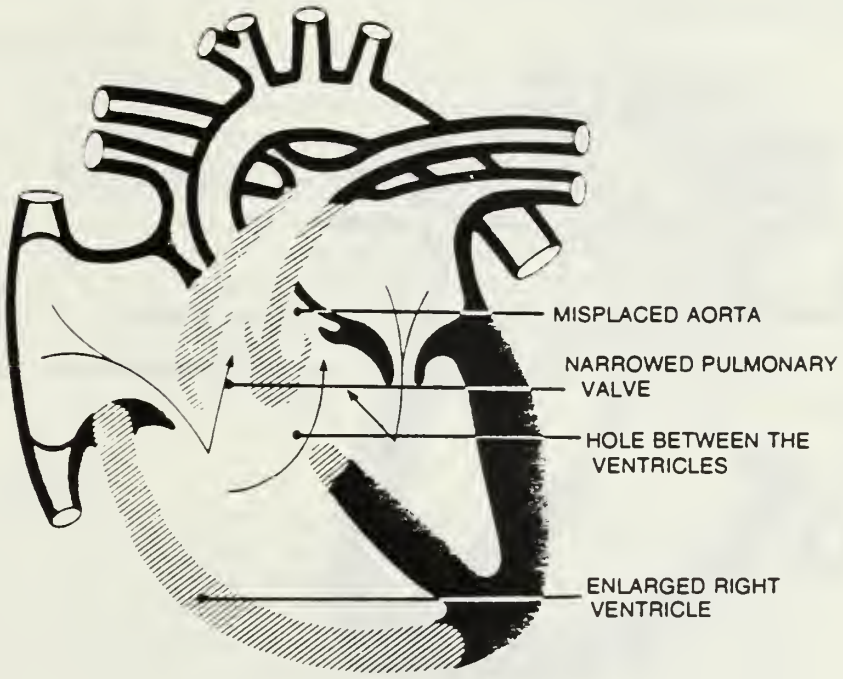
Blood leaks through a hole in the wall between the ventricles, usually from left to right. Large defects may strain both ventricles, particularly the left.



Common Heart Defects

Tetralogy of Fallot

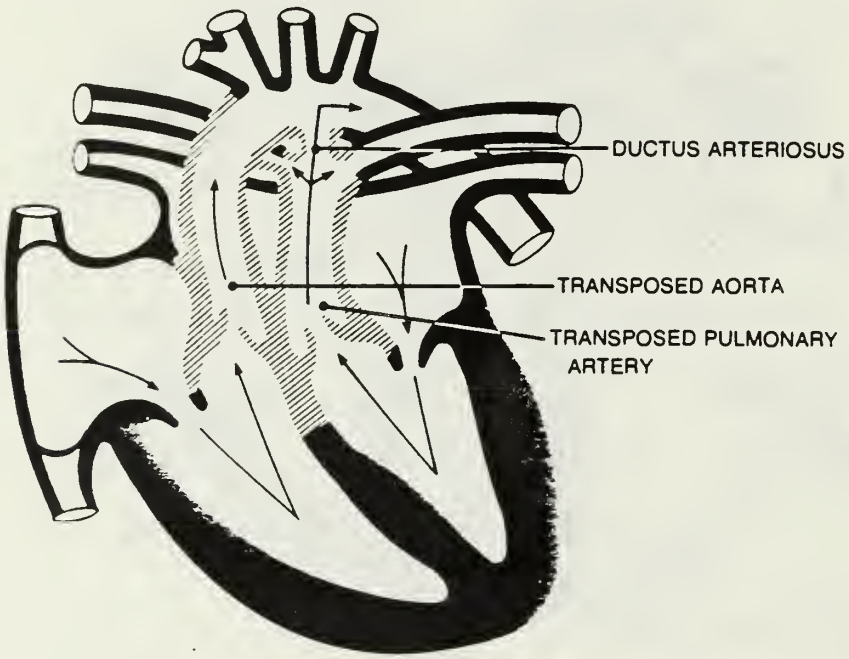
A combination of four defects causes deoxygenated blood to mix with oxygenated blood and be carried to the body:



Tetralogy of Fallot

Transposition of the great arteries

The aorta and pulmonary artery are attached to the wrong ventricles. Deoxygenated blood is carried to the body, oxygenated blood to the lungs. A patent ductus arteriosus and septal defect, if present, allow some oxygenated blood to reach the rest of the body, making life possible. Newborns with this defect usually require immediate palliative surgery prior to definitive correction.



Transposition of the Great Arteries

CAUSE

When the embryo is just 23 days old, the heart begins to beat. The rapidly developing heart is particularly susceptible to deleterious influences during early fetal life. In most cases the specific cause for congenital heart disease is not identifiable. There is a suspected association with teratogens—that is, agents or factors (viruses, drugs, excessive radiation) which cause physical defects in the developing embryo. However, there are cases of identical twins in which one developed CHD and the other did not, even though both were presumably exposed to the same environment in the uterus. CHD may also be caused by new gene mutations and other genetic factors. (It is linked, for example, with a number of chromosomal abnormalities, including those responsible for Down and Turner syndromes.

INCIDENCE

About eight out of every thousand people have cardiovascular malformations. The chances of having a second child with a heart defect is 2 to 5 percent; they may be even greater if two children in one family are already affected. The prevalence of malformations among children whose parents have congenital heart disease is 3 to 4 percent.

DETECTION

Serious CHD is often recognizable at birth; the newborn shows breathing difficulties and remains blue despite the administration of high concentrations of oxygen. While the physical examination, chest X-ray, and tracing of the electrical activity of the heart (electrocardiogram) may indicate the presence of heart disease, other, more sophisticated tests are often necessary to determine the type. One newer, useful diagnostic technique is echocardiography: sound waves are bounced off the heart to produce an image of its structures on paper or a television screen. It is sometimes necessary to obtain an exact outline of the heart structures and to chart the flow of blood through it by a procedure called cardiac catheterization, which involves injecting dye into the heart via a tube threaded through blood vessels.

COURSE

How seriously the child will be affected by congenital heart disease depends upon the type and severity of the problem. Some defects (ASD, VSD) may be so minor that the child will tolerate them well and no specific corrective procedures will be necessary. In such cases, the child's condition is followed very closely, and corrective procedures are considered only if there are signs of worsening. Severe malformations, however, such as those in which the blood bypasses the lungs (TGA or TOF), can be life-threatening unless treated early. If, due to small size or poor health, the child is not able to withstand major corrective surgery, it may be necessary to perform temporary surgical procedures which allow for adequate oxygenation of the blood.

ACCOMPANYING HEALTH PROBLEMS

During the first few years of life, children with significant heart defects are often in and out of the hospital, where they are treated not only for the heart condition but also for secondary medical problems, such as pneumonias, poor feeding, or infections. Other secondary problems are of particular importance. Among these is congestive heart failure, a condition in which the heart, having to work extra hard, becomes strained and does not pump as efficiently as it should, causing fluid to back up into the lungs, liver, and other organs. Drugs such as digitalis and water

pills (diuretics) are generally effective in preventing and treating this complication.

The altered anatomy of the heart, including narrowed valves or holes between heart chambers, is conducive to the growth of bacteria, which can damage the heart even further. Clumps of bacteria may even break off and lodge in the brain, causing abscesses. Such serious complications must be identified and treated with antibiotics as quickly as possible.

The degree of severity of congenital heart disease determines the effects it will have on growth and development. The incomplete oxygenation of blood and extra caloric expenditure that accompany the most severe forms of this condition result in poor growth of tissue, causing the child to be small and underdeveloped. Serious conditions also cause poor appetite (with resultant inadequate caloric intake) and frequent hospitalizations for surgery and secondary illnesses. The less severe types of heart defects, on the other hand, are not likely to significantly interfere with normal growth and development.

MEDICAL MANAGEMENT

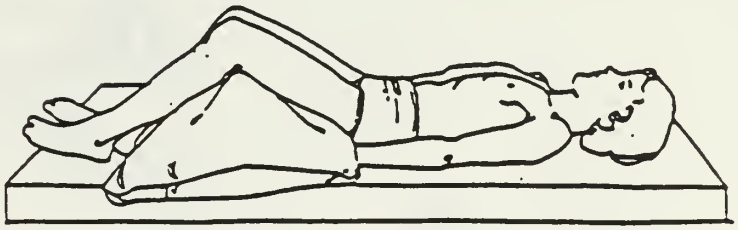
The main features of management include early identification, medical and physical stabilization prior to corrective surgery, rehabilitation following surgery, and—of special importance—nutritional and developmental assessment and treatment before, during, and after surgery.

IMPLICATIONS FOR EDUCATION

Oftentimes, frequent hospitalization, coupled with the unstable medical condition of children with congenital heart disease, diverts attention away from learning and development. It is almost impossible to determine the potential for children in such circumstances. Nevertheless, growth of the brain and other tissues is rapid during the first several years, and attention to developmental needs cannot be postponed until after surgery and medical management are complete. Thus, early intervention professionals in home- or center-based programs must work closely with the medical team to determine how the child's development can be coordinated most efficiently with medical management. Once early intervention personnel understand both the nature of the heart condition and the rationale for treatment, they can bring their performance expectations in line with the child's physical limitations. They can also observe the child for fatigue, poor appetite, or other warning signs of setbacks or complications. Congenital heart disease is a good example of how important it is for medical and education-related professionals to work together for the child's optimal treatment in the early years.

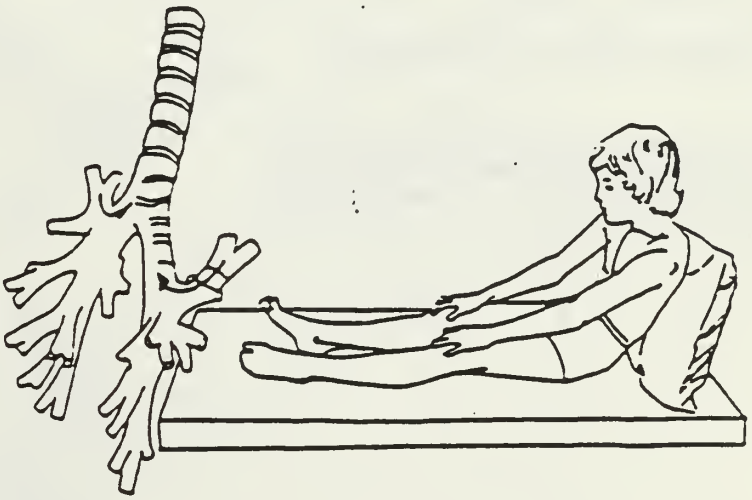
UPPER LOBES
Anterior Segment

Bed or drainage table flat. Patient lies flat on back with pillow under knees. (Clap between clavicle and nipple on each side of chest.)



UPPER LOBES
Apical Segment

Bed or drainage table flat. Patient leans back on pillow at 30 degree angle. (Clap over area between clavicle and top of scapula on each side.)

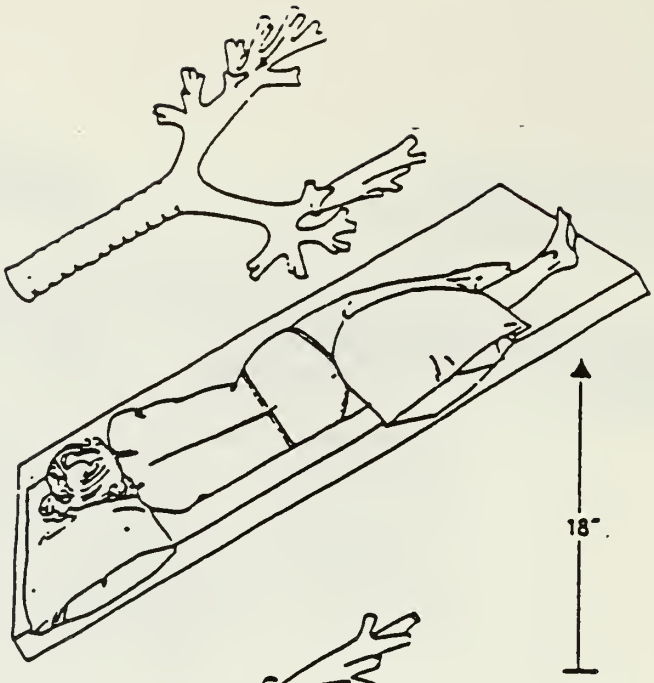


CLAPPING

Clapping with a cupped hand on the chest wall over the segment to be drained is thought to set up vibrations which are transmitted to the bronchi and may help dislodge secretions. The hand is cupped as shown, holding the fingers together so that the contour of the cupped hand conforms with the chest wall. The patient is encouraged to take a deep breath and cough after clapping. Clapping is performed only when ordered by the physician.

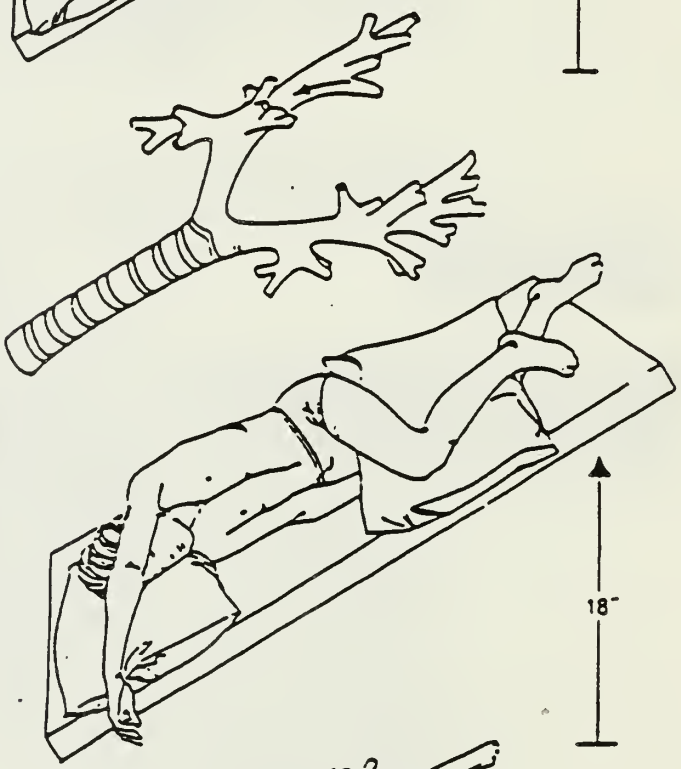
LOWER LOBES
Lateral Basal Segment

Foot of table or bed elevated 18 inches or 30 degrees. Patient lies on abdomen, then rotates ¼ turn upward. Upper leg can be flexed over a pillow for support. (Clap over uppermost portion of lower ribs.)



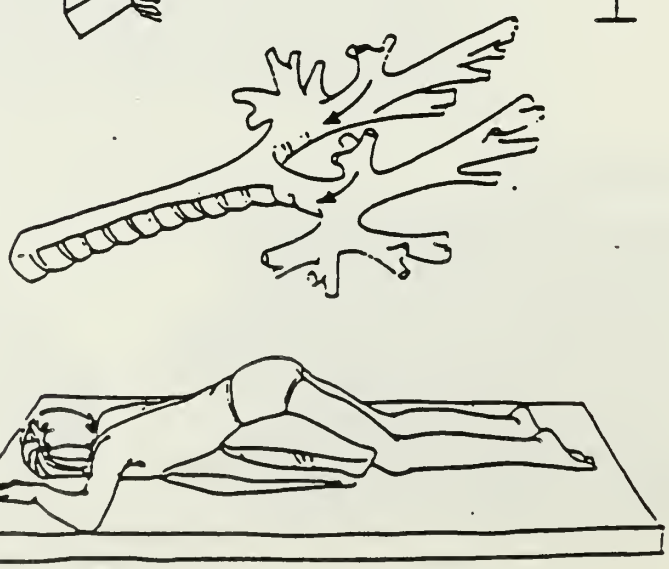
LOWER LOBES
Anterior Basal Segment

Foot of table or bed elevated 18 inches or 30 degrees. Patient lies on side, head dow pillow under knees. (Clap over lower ribs just beneath axilla.)



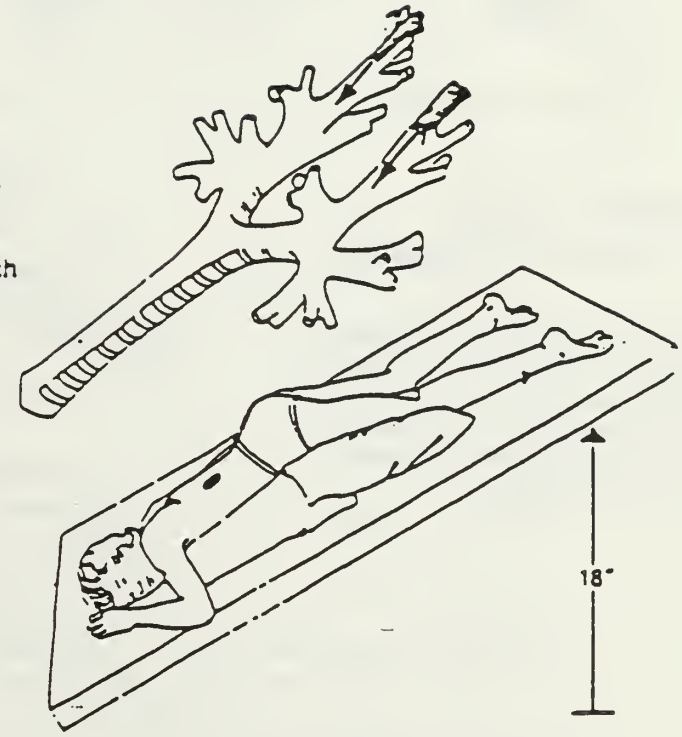
LOWER LOBES
Superior Segment

Bed or table flat. Patient lies on abdomen with pillows under hips. (Clap over middle of back below tip of scapula on either side of spine.)



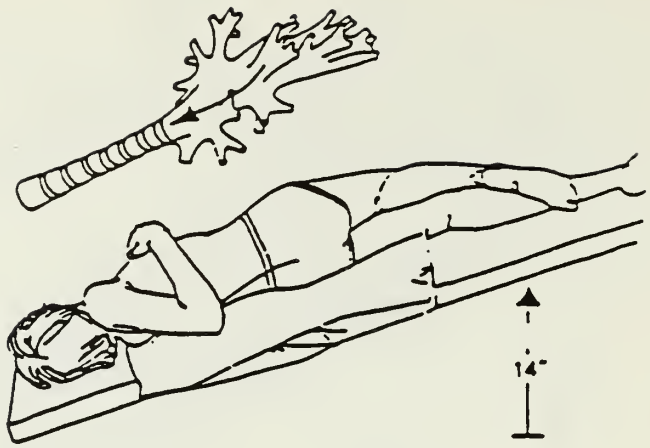
LOWER LOBES
Posterior Basal Segment

Foot of table or bed elevated 18 inches or 30 degrees. Patient lies on abdomen, head down, with pillow under hips. Upper leg can be flexed over a pillow for support. (Clap over lower ribs close to spine on each side of chest.)



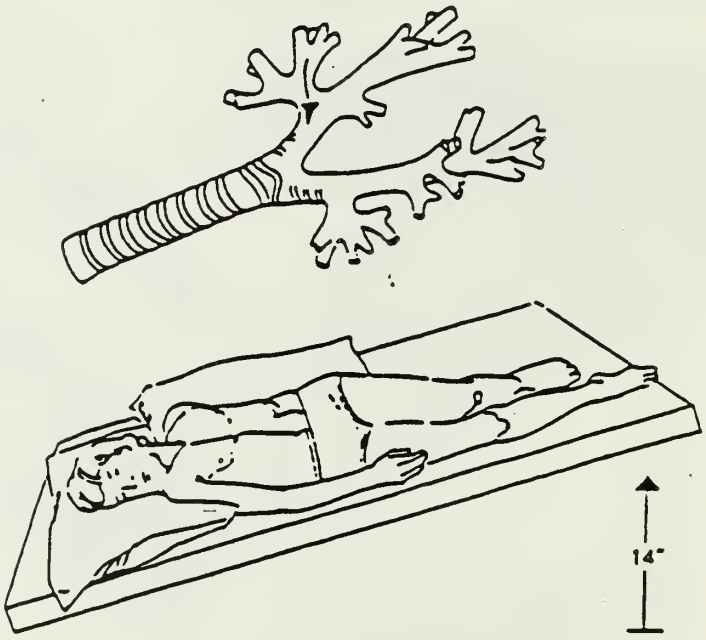
RIGHT MIDDLE LOBE
Lateral Segment
Medial Segment

Foot of table or bed elevated 14 inches or about 15 degrees. Patient lies head down on left side and rotates ¼ turn backward. Pillow may be placed behind patient from shoulder to hip. Knees should be flexed. (Clap over right nipple area.)



LEFT UPPER LOBE
Lingular Segment-Superior
Inferior

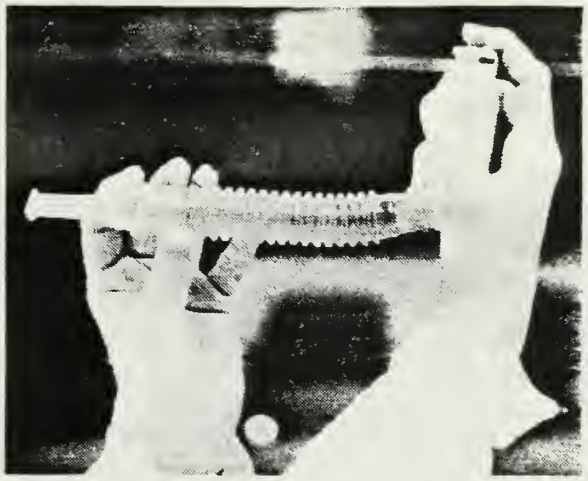
Foot of table or bed elevated 14 inches or about 15 degrees. Patient lies head down on right side and rotates ¼ turn backward. Pillow may be placed behind patient from shoulder to hip. Knees should be flexed. (Clap over left nipple area.)



UPPER LOBES
Posterior Segment

Bed or drainage table flat. Patient leans over folded pillow at 30 degree angle. (Clap over upper back on each side of chest.)

"how to" properly use your inhaler



1. Sit up very straight, shoulders back.
2. Shake inhaler well and attach to tubing.
3. Place mouthpiece in mouth, keeping teeth and tongue out of the way.
4. Pinch off nose.
5. Push down top of inhaler and breath in deeply.
6. Hold breath and count to five slowly.
7. Breath out slowly.

Repeat steps 1-7 for each puff prescribed by doctor.

8. Remember to clean the tube, mouthpiece and plastic container each day and store in a cool, dry place.
9. Do not use the inhaler more than 4 times daily unless otherwise directed by your doctor.
10. If you are using a bronchodilater inhaler (Albuterol, Metaproterenol, Isoproterenol), contact your doctor if the following occurs: fast heartbeat; nervous, anxious feeling; tremors; nausea and vomiting.
11. If you are using a steroid inhaler (Beclomethasone or Dexamethasone), contact your doctor if the following occurs: mouth irritation; difficulty in swallowing; cream-colored patches in your mouth or throat; or fever.

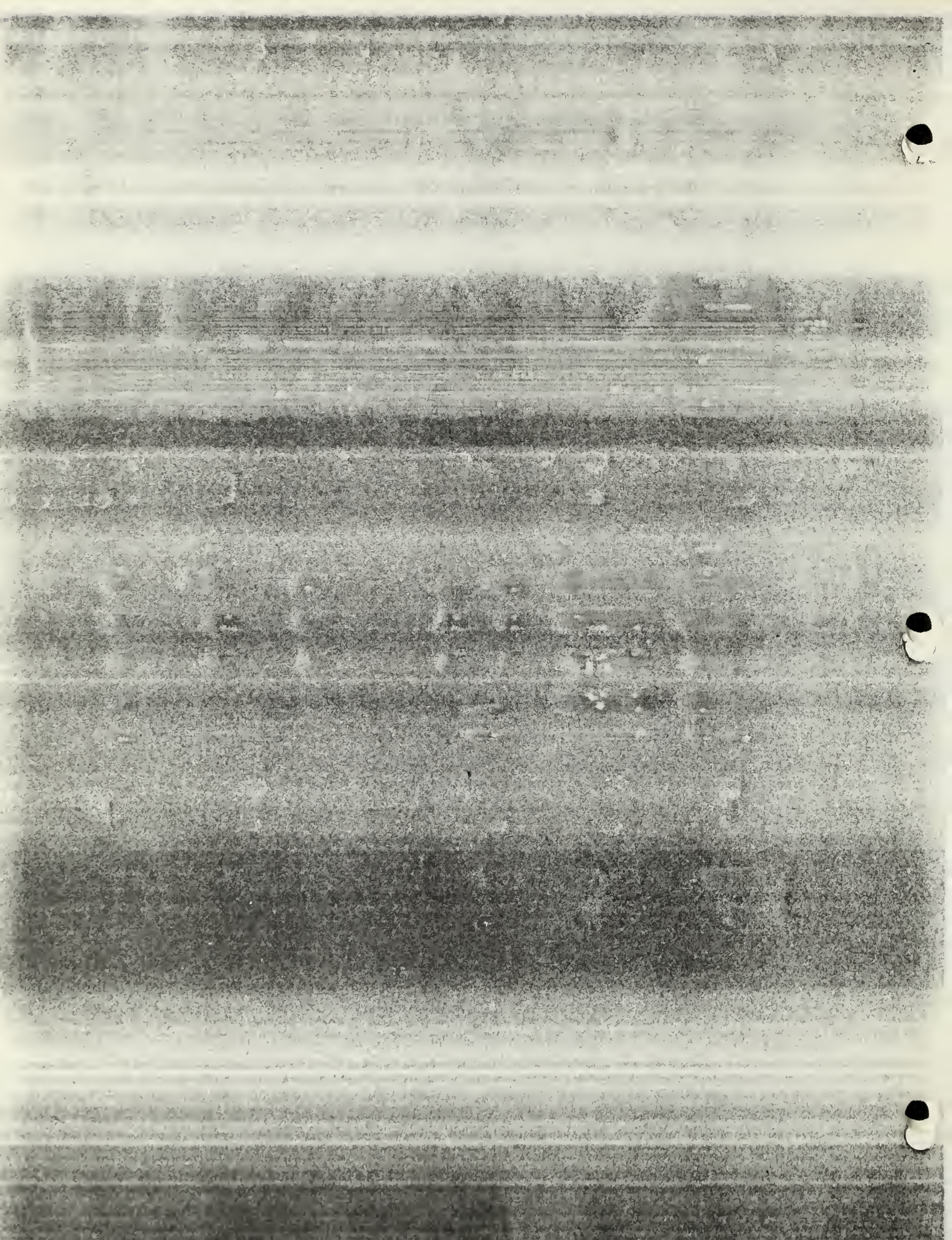
REMEMBER:

- **Follow instructions carefully.**
- **Store medications out of the reach of children.**

ARKANSAS CHILDREN'S HOSPITAL

Pharmacy Department **Phone (501) 370-1223**

Presented as a professional service of your pharmacists and the Pulmonary Medicine Department.



Behavior Management

Objectives

After this workshop, participants will be able to:

1. Define behavior and describe it in specific observable terms.

2. Identify multiple functions of behavior.

3. Become competent in utilizing the ABC method of behavioral intervention

4. Assess, identify and work with families and outside resources useful in addressing behavioral issues.

5. Demonstrate knowledge of behavioral terminology.

What Is Behavior?

Behavior is an observable (measurable) action performed by an individual. It is what the person does. In behavior management terms, a behavior can also be referred to as a response.

Function of Behavior

All behavior has its root in people's attempts to meet their own needs and may therefore have any number of immediate functions, including any one or more of the following:

-gaining attention or control

-sensory stimulation or relief

-escape or avoidance of an unpleasant situation

-achieving a pleasant experience

-communication of a feeling, need or desire

What Is Behavior Modification?

Also described as behavior management, operant conditioning and behavior therapy, Behavior Modification is a set of procedures designed to effect changes in an individual's behaviors (actions).

All behavior is affected by consequences (what occurs after the behavior) and antecedents (what occurs prior to the behavior). Behavior management principles are based on the relationship between changes in the environment and changes in an individual's responses to particular behaviors.

Why Use Behavior Management?

The most prevalent use of behavior management is to teach new skills to a person. Additionally, behavior management is used to assist a person in eliminating inappropriate behaviors which may cause injury to self or others, or cause one to be less accepted by other people.

Although the effectiveness of behavior management techniques are rarely disputed, there is often a negative reaction to the concept. Some common concerns about the use of behavior management are:

- it gives people too much control over others.
- it is negative and involves extensive use of punishment.
- it is unnatural to reward people for something they should do anyway.
- it does not take into concern as person's feeling or individuality.

Behavior management is based on the principals of positive reinforcement, which has been found to be more effective than punishment in changing or learning new skills and behaviors. People control and influence others' behaviors whether they intend to or not.

Studying the circumstances surrounding a behavior gives people information so that they may effectively and responsibly use the techniques in a manner which is considerate of one's feelings and individuality.

Should I Attempt to Change This Behavior? Some Factors to Consider

Most behaviors in and of themselves do not necessarily have negative or positive connotations and cannot, in isolation, be deemed either

"appropriate" or "inappropriate." Spitting, for example, is not considered proper on the streets of American cities, but in some cultures it is totally acceptable. Similarly, though jumping on a trampoline is encouraged, jumping while standing in line at a grocery store is not typical and therefore, someone who is jumping repeatedly in line is likely to draw a lot of attention. People may even begin to move away from the person or give him or her strange looks, particularly if the person jumping is an adult; that is, unless the store is having a jump-a-thon for a local agency or group.

Often times the rules governing social behavior are quite subtle, as alluded to above, these rules vary according to factors such as the CONTEXT in which the behavior is occurring and the AGE of the person doing the behavior. It is therefore important to consider both when comtemplating trying to change a child's behavior.

With regard to the former, examine whether the behavior is really problematic in the CONTEXT in which it is exhibited. If it is, and the decision is to try to change the behavior and substitute some other behavior which is more appropriate to the context, ask yourself whether this new behavior:

- is important for the child to learn;
- will help improve his or her quality of life;
- will help the child feel more competent;
- can be practiced frequently; and
- would have to be done by someone else if the child could not.

With regard to the second factor, AGE, it is important to remember that certain behaviors serve important functions in furthering a child's cognitive, sensory and motor development, annoying though they may be for the child's parents. Examples include: dropping food on the floor repeatedly and laughing; eating inedible objects; pulling food or other objects off shelves at home or in stores. How any of these behaviors is addressed if done by a one-year-old may be different from the strategies used if the person doing them is a twenty-year-old woman with mental retardation. Similarly, the two-year-old who persists in saying "no" to every question asked will be dealt with differently from the fifteen-year-old teenager with diabetes who refuses to follow a prescribed diet, though both individuals may be trying to let people know that they want to exert some control over their lives.

Finally, there are other factors which parents of children who have disabilities or chronic illnesses may need to consider as they seek to foster their children's development and contemplate ways of addressing some of the challenges their children may present. These may include:

- the child's prolonged dependency on other people, which may clash with his or her need to become more independent;

- concerns for a child's safety and physical well-being such as the need to adhere to specified routines or regimens of care while also wanting the child's and the family's routines and lifestyle to be as typical as possible. The child's desire for increasing levels of independence and his or her wish to conform with peers may make adherance to these regimens difficult and may be cause for tension in the family; and

- concerns about how other people may view particular interventions being used with a child with a disability.

Some of these issues are explored in articles and excerpts included here, such as:

"Adolesence," Chapter 15 in Monica Loose Jones' book, Home Care for the Chronically Ill or Disabled Child. New York: Harper and Row, 1985. Note especially page 207.

Goldfarb, L.A., M.J. Brotherson, J.A. Summers, and A.P. Turnbull. Meeting the Challenge of Disability or Chronic Illness: A Family Guide. Baltimore,MD: Paul H. Brookes Publishing Company, 1986, Pages 113-115.

The ABCs of Behavior Management

Antecedent refers to the events or situations which occur just prior to a behavior. Seeing a particular person, being asked to do something, being in a certain room, being tired, and hearing noises are examples of antecedents which may directly or indirectly guide one to behave in a certain way.

Behavior refers to the action which follows the antecedent and precedes the consequences; smiling, throwing objects, refusing to do a task, stamping feet, and washing dishes are examples of behavior (responses) that may follow antecedents and/or precede consequences.

Consequences refers to the events, situations or results which occur immediately following a behavior; a hug, a paycheck, reprimands, being ignored, attention, and praise are examples of consequences which effect behavior.

ABCs can be used to develop a program to teach a new behavior or eliminate a behavior.

Why Behaviors Are Problematic

Identifying the specific behavior, its consequences and antecedents (conditions under which behaviors occur) is the first step in developing a program to change problematic behavior. Determining how often, or for how long, the behavior occurs originally allows one to measure whether a program has actually been effective in changing behavior.

In order to teach a new behavior, one must identify and then arrange both the antecedents and the consequences which will surround the new behavior.

Behavioral Intervention

An intervention program is the arranging and/or structuring of antecedents and consequences to encourage the desired behavior. The decision to intervene is usually based on a desire to teach new behaviors or eliminate inappropriate behaviors.

Behavior followed by pleasant consequences is more likely to happen again.

Rearranging and/or structuring the conditions which precede (antecedents) a behavior can guide a person in a positive way.

Problem-Solving Sequence

This sequence can be applied to develop solutions for any problem, though the focus here will be on addressing behaviors which have become problematic.

I. DEFINE AND DESCRIBE THE PROBLEM

This may include an examination of any or all of the following:

- WHAT is happening: measurable, concrete terms. This is presented in more detail on the following pages.
- WHO is involved?
- WHERE is it happening?
- WHEN/UNDER WHAT CONDITIONS is it happening?
- What are the typical CONSEQUENCES of the behavior?
- What does your child seem to be SAYING with the behavior?
- Describe PREVIOUS ATTEMPTS to address the problem.

II. BRAINSTORM possible methods for addressing the problem, including everyone who is somehow affected by the problem.

Consider changing what happens before the behavior (ANTECEDENT)and/or what typically follows it (CONSEQUENCE).

III. EVALUATE THE ALTERNATIVES

You may want to consider some of the exercises included in your handouts as you examine each of the alternatives and try to determine which may be more feasible for your family.

These exercises have been taken, in their original form, from:

Goldfarb, L.A., M.J. Brotherson, J.A. Summers, and A.P. Turnbull. Meeting the Challenge of Disability or Chronic Illness: A Family Guide. Baltimore, MD: Paul H. Brookes Publishing Company, 1986.

IV. CHOOSE ONE OF THE ALTERNATIVES

Consider factors such as:

- lowest cost (financial and other);
- most potential impact;
- least resistance;
- availability of needed resources and people; and
- other criteria which are important to the family.

Once the strategy has been selected, plan it in detail:

- Plan out the steps involved.
- Assign responsibilities.
- Develop a way to monitor progress.
- Anticipate potential problems (e.g., escalation of behavior) and plan for them.

V. TAKE ACTION: USE REINFORCEMENT (see handouts)

VI. EVALUATE RESULTS OF EACH STEP

References:

APT Project, materials and notes from workshop entitled: "Parent-Professional Partnerships", April 27, 1985.

Baker, Bruce, Behavior Problems, Research Press, Champaign, IL.

Goldfarb, L.A., M.J. Brotherson, J.A. Summers, and A.P. Turnbull. Meeting the Challenge of Disability or Chronic Illness: A Family Guide. Baltimore, MD: Paul H. Brookes Publishing Company, 1986.

Taking Care of Yourself and Your Family

Everyone in a family has individual needs and all families need to find ways to balance the needs of individual members. For families to be able to attend to the extra needs which a child with a disability or a chronic illness may have, other family members must find ways to make sure that their own needs are being met as well. The ideas and articles which follow include some suggestions which may be useful for your family or another family you may know.

Identify and know your strengths as a family and as an individual. Use again those strategies which work well for you and drop those which do not, rather than dwelling on them.

Treat yourself; you deserve it! Make sure you give youself special treats on a regular basis.

Develop small, attainable goals for you and your child.

Know your limits. Develop contingency and back-up plans so that when you need a break, you can be reasonably assured of getting one. Know whom you can count on and make use of these supports.

Know your allies within agencies and the community.

Find other parents to talk to; you are not alone.

Anticipate problematic situations and plan for them. For instance, if your child has trouble waiting and you anticipate delays at a clinic, take along toys, books and a nutritious snack. Boredom and hunger make waiting intolerable.

Help your child to develop increased tolerance for frustrations and socially acceptable ways of dealing with them.

Help your child to communicate his or her thoughts and feelings.

Provide your child with as much control over his or her life and body as possible. Even when strict regimens of care must be adhered to, he or she may be able to choose, for instance, which exercise to do first or which room to do a certain procedure in.

Know your own and your child's rights.

Be aware of resources available to you, your family and your child. Stay informed by reading newsletters, joining parent's groups, etc.

Find ways to have input into the care and services you and your child are getting. Join local parent groups. School have Parent Advisory Councils (PACs) for parents and children who are receiving special education. Some hospitals have committees which include parents. Local and state agencies often have advisory boards which include parents and other family members. Keep local legislators informed of needs your child or family has which are not being adequately addressed. When you know that legislators are going to be voting on legislation which could affect your child and family, let them know how you feel about it. They don't often get a lot of calls or letters on specific bills, so your contact could make a real difference.

Learn relaxation techniques.

COMMUNITY RESOURCES:

GAINING ACCESS

Objectives

After completion of the workshop, participants will:

1. Understand the functions of various state agencies that serve handicapped children.

2. Find medical, economic and educational resources for the children under their care.

3. Know where to turn for help in securing these services

4. Learn some of the ways that others have overcome obstacles to securing services.

Community Resources:

Gaining Access

The community affects many aspects of a child's development by the quality and quantity of its support. This unit on community resources identifies some primary support services and information available to assist the family with a child who has a disability. The material is presented in the following four broad topic areas:

1. Social Services (public agencies and private organizations)
2. Education
3. Finances
4. Medical Care

These are brief and definitely not exhaustive descriptions, intended only as a starting point. Please refer first to the supplemental materials in the back of the unit. More information is provided about the Departments of Public Health and Public Welfare because of their primary roles in health care for children with multiple handicaps. All of the agencies listed, except the Department of Education and the federal Social Services Administration, are administered by the Executive Office of Human Services (EOHS). EOHS is the Governor's executive agency which coordinates the policies, budgets and services provided by this system of human service agencies.

It is important to recognize that legislators have a significant role in setting policy and funding programs. Know your state and city legislators and contact them. Advocate for your interests. They want your questions and your opinions.

State Agencies

Department of Public Health (DPH)
150 Tremont Street
Boston, MA 02111
727-2700

A broad range of programs carries out the Department's mandate to "maintain, protect and improve the health and well-being of the people of the Commonwealth."

The Department's Division of Family Health Services works to promote the health of Massachusetts women and children and support their families through two broad program areas: Services for Handicapped Children (SHC) and Maternal and Child Health (MCH). Their program units are as follows:

Services for Handicapped Children (SHC)

Case Management Services	727-8925 (or see regional listing following page 140)
Clinical Services	727-5812 (or see regional listing following page 140)
Community Services	727-5822
Early Childhood Development Services	727-5089

Maternal and Child Health (MCH)

Perinatal and Genetics	727-0944
Preschool and School Health	727-0944
Primary Care	727-0941
Women, Infants and Children	727-6896
Women's Health	727-7222

Department of Public Welfare (DPW)
600 Washington Street
Boston, MA 02111
727-2700

The Department of Public Welfare is responsible for administering programs which provide financial and/or medical assistance to families who meet the financial eligibility criteria. The major programs are as follows:

Medicaid

- pays for some medical care, prescriptions, supplies and in-home medical assistance. Families receiving AFDC and all persons receiving SSI are automatically eligible.
- persons with excessive medical costs may still be eligible with a "medical spend-down."

Project Good Health (PGH)

- links Medicaid-eligible children, [illegible] to 21 years of age, to sources of primary medical and dental care.

Food Stamps

- stamps issued monthly, based on need, to be used to purchase food
- eligible if SSI or AFDC recipient or if financial criteria met

Aid to Families with Dependent Children (AFDC)

- needs-based cash assistance program
- pregnant women with no other children are eligible for a one-person grant starting in the fifth month of a medically verified pregnancy
- available to needy children deprived of support due to parental absence, incapacity or under-employment, and to certain caretaking relatives

(continued)

Emergency Assistance

- needs-based program for specified urgent needs (i.e., after eviction, fire, flood, etc. May pay for moving, housing, fuel, repairs, etc.)
- available once every 12 months to families with children as well as pregnant women (any stage of pregnancy)

General Relief/Medical Assistance

- needs-based program for non-employable adults, families and children not eligible for other programs
- provides emergency relief for disasters, evictions, etc.
- provides minimum medical assistance

Department of Mental Health (DMH)
160 North Washington Street
Boston, MA 02114
727-5600

DMH services range from minimal out-patient services to intensive clinical treatment and/or in-patient services, including:

- counseling
- crisis centers/emergency services
- in-patient care
- after-care
- children and adolescent services

Department of Mental Retardation (DMR)
160 North Washington Street
Boston, MA 02114
727-5608

This new agency was created in July 1987 from the mental retardation division of the Department of Mental Health. As a new agency, much of the work this first year will be transition and planning activities. Some area offices are open.

Department of Social Services (DSS)
150 Causeway Street
Boston, MA 02114
727-0900

Parental Stress Line 1-800-632-8188 or 437-0110

Child at Risk (to report) 1-800-792-5200

Parents Anonymous 1-800-882-1250

Social services are provided to children, adolescents, families and disabled adults to support and strengthen families, protect children from abuse and neglect, and provide children in the state's care with permanent homes. Services include:

- adoption
- camperships
- child care
- case management
- counseling
- respite care for the developmentally disabled
- parent education and aid
- protective services (child abuse and neglect)
- emergency shelter for children
- substitute care (foster care, specialized foster care, residential treatment)
- services to women in transition (battered women)

Massachusetts Commission for the Blind (MCB)
110 Tremont Street
Boston, MA 02111
727-5556
1-800-329-6450

- MCB assists blind people of all ages in overcoming barriers to living independently by providing:

- medical assistance
- social rehabilitation
- vocational rehabilitation
- children's services
- respite
- adaptive housing program

Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)
600 Washington Street, Suite 600
Boston, MA 02111
727-5106; TDD 727-5236

The principal agency advocating for the rights of the deaf and hard of hearing provides the following services free of charge, based on need:

- information and referral
- advocacy
- publications
- interpreter referral service (limited funds)
- TDD (telecommunication distribution program--limited funds)
- independent living skills services

Office For Children (OFC)
150 Causeway Street, Room 901
Boston, MA 02108
727-8900

as of 12/87:
20 West Street
Boston, MA 02111

The OFC advocates for children's services through the following programs:

- Local Help for Children offices provide individual advocacy, information and assistance.
- Local Councils for Children, composed of community volunteers, identify local needs and recommend development of programs.

(continued)

- The Central Interdepartmental Team serves as a planning body to review cases requiring extensive state agency coordination and services.
- Licenses and monitors daycare providers, foster and adoption agencies and group homes.
- Funds 12 child care resource centers.

Massachusetts Office of Handicapped Affairs (OHA)

In Boston: Room 1305
One Ashburton Place
(617) 727-7440 or
1-800-322-2020 (voice and TDD)

In Falmouth: 22 Cahoon Court
Falmouth, MA 02534
(617) 548-0973 or
1-800-368-1919 (voice and TDD)

In Northampton: c/o Department of Public Health
23 Service Center Road
Northampton, MA 01060
(413) 586-7525, ext. 62

- client assistance program helps with vocational rehabilitation problems, independent living services, employment and housing discrimination and transportation matters
- advocacy for improved service delivery system and rights of the disabled

Massachusetts Rehabilitation Commission (MRC)
20 Park Plaza
Boston, MA 02116
727-2183

The Mass. Rehab Commission assists teenagers and adults with disabilities to develop or regain their employability by providing:

(continued)

- evaluations, counseling and job placement services without consideration of financial need
- employment-related goods and services, such as skill training or education, extended sheltered employment, personal care assistance, and mobility aids to those who meet financial and disability eligibility guidelines
- the Statewide Head Injury Program (SHIP), for persons who have received externally caused traumatic head injury

Department of Education (DOE)
1385 Hancock Street
Quincy, MA 02169
770-7500

The Department of Education is responsible for oversight of educational services throughout the state and provides:

- instructional information and support to school districts
- regional centers which serve as clearinghouses for questions concerning both regular and special education

Massachusetts Developmental Disabilities Council (MDDC)
600 Washington Street
Boston, MA 02111
727-6374

Serving as the State Planning Council for the developmentally disabled, MDDC's principal responsibilities are:

- to develop, implement and evaluate, jointly with the Administering Agency on Developmental Disabilities, the state plan for services to the developmentally disabled
- to review and comment on all state plans in the Commonwealth which relate to programs affecting persons with developmental disabilities
- to serve as an advocate for persons with developmental disabilities

Members of the Council are appointed by the Governor and must be Massachusetts residents.

Massachusetts State Veterans Programs
100 Cambridge Street
Boston, MA 02202
727-3578

- apply at local Veterans Services Department office; often based at town hall
- needs-based state and locally funded program for qualifying veterans and their families (children, spouse, widow, widower, parents)
- pays a basic grant
- provides hospital/medical payments

Federal Social Security Administration

Supplemental Security Income (SSI)

- needs-based entitlement program for adults and children who meet the disability and financial criteria
- provides Medicaid and monthly financial benefit payment
- apply at local Social Security Administration Offices

Survivor's Benefits

- families may be eligible for benefits based on the earnings of the deceased member

Private Advocacy, Information and Legal Agencies

Besides using state services, particularly the Department of Public Health case management units and Office for Children advocates, the following organizations are excellent resources on a wide range of topics.

(continued)

Federation for Children with Special Needs
312 Stuart Street
Boston, MA 02116
482-2915

A parent-staffed national advocacy organization providing useful resource materials, parent trainings, conferences and advocacy on disability issues on the state and national level.

Information Center for Individuals with Disabilities (ICID)
Statler Office Building
20 Providence Street
Boston, MA 02116
727-5540
1-800-462-5015
(TTY) 727-5236

The ICID maintains information fact sheets on a great variety of services, topics and diseases besides publishing an excellent monthly newsletter.

Disabilities Law Center
11 Beacon Street
Suite 925
Boston, MA 02108
723-8455 (voice and TTY)

This organization provides free legal service to individuals with disabilities. Local offices are available and legal representation can be provided. They are experts in the field of Chapter 766 as well as SSI.

Specific Support Services

There are many support services that all families need. These may be more costly, needed more frequently, or need to be especially adapted, if a family member is disabled. The following list covers only some major service areas and is far from exhaustive. Additional information and services may be available from the previously mentioned state agencies and advocacy organizations.

Adaptive Equipment Loan Programs

- Easter Seal Equipment Loan Program 1-800-922-8290

  Wheelchairs, walkers, and other pieces can be borrowed free of charge; donations of equipment are tax deductible

- North Shore Association for Retarded Citizens

  Adaptive Equipment Exchange 744-1225

  Primarily serves the North Shore

- DPH regional clinics, local home health agencies, and early intervention programs often make equipment available for loan to their clients.

- DMH state schools' adaptive equipment departments are often able to respond to community requests to adapt specific equipment.

Counseling/Parent Support Groups

- Contact the Massachusetts Developmental Disabilities Council for its directory entitled Support Groups and Networks for Parents and Siblings of Individuals with Developmental Disabilities

- Ask specialists, clinics or organizations serving the specific disability.

- See information/advocacy/legal agencies listing

- Call the Massachusetts chapter of the National Association of Social Workers for referral to individual, family, and group therapists: 227-9635

Housing

Contact local housing authorities for local information about Community Development Block Grants and subsidized, accessible and adapted housing units.

Adaptive Environments Center
Massachusetts College of Art
621 Huntington Avenue
Boston, MA 02115
739-0088

- Information regarding reorganizing and/or constructing environments to suit particular populations

Health Care Financing Administration (HCFA)
J.F. Kennedy Building
Government Center
Boston, MA 022-3
565-1232

Mass. Housing Finance Agency (MHFA)
50 Milk Street
Boston, MA 02109
451-2766

Call either of these agencies for low-cost home mortgages.

Independent Living Centers
Massachusetts Rehabilitation Commission
727-4828

- Apply locally for Title 7 part A funds for adaptive housing services.

Information Center for Individuals with Disabilities (ICID)
20 Park Plaza, Room 330
Boston, MA 02116
727-5540 (voice)
1-800-462-5015 (TTY)

Call or write ICID for their new fact sheets including:

- a listing of local housing authorities

- a bibliography on accessible home design

Nutrition

Nutrition Resource Information for Families and Caregivers of Special Needs/Handicapped Children, Department of Public Health, Services for Handicapped Children, Cynthia Bayerl.

This is an excellent, comprehensive guide specific to children with disabilities.

Sports and Recreation

Information Center for Individuals with Disabilities (ICID) (fact sheets)

Massachusetts Association for Retarded Citizens (ARC)

Massachusetts Special Olympics Program

Project Adventure, Inc.

Jewish Community Center of Greater Boston

Arts/Music

Very Special Arts, Massachusetts (VSA)

Center for Creative Art Therapies (CCAT)

Community Music Center of Boston (CMC)

All-Newton Music School

Respite/Home Health Care/Child Care

These are similar services that may be named differently depending on the funding source, the level of care required by the child, and whether the parent is to be assisted or totally relieved of care responsibility for a short period.

State Agencies: DSS, DMR, DPH, MCB

Contact these agencies for information about disability criteria, program type, and amount of service

(continued)

Medicaid

- programs through Dept. of Public Welfare and Mass. Commission for the Blind both provide medically necessary services (nurses, aides, specialty therapists) through certified (meets Medicaid regulations and is approved for Medicaid funding) home health agencies and Visiting Nurses Associations
- private duty nursing service requires prior approval from Medicaid central office
- home health aide and other services are arranged directly with the certified home health agency or Visiting Nurses Association
- services must be ordered by a physician

Insurance

- benefits for home health care and private duty nursing vary widely
- usually must be determined medically necessary
- often service must be arranged at time of hospital discharge
- many home health agencies will help you investigate these benefits

Private Pay

- inquire at your respite provider agency about additional private service
- inquire at Office for Children about their child care resource centers and assistance in locating family and center-based day care providers and after-school programs

Obtain listings of home health agencies from:

Mass. Assn. of Community Health Agencies
6 Beacon Street, Suite 914
Boston, MA 02108
523-0610

(certified and non-certified agencies)

(continued)

Mass. Council for Homemaker-Home Health Aide Services, Inc.
34 1/2 Beacon Street
Boston, MA 02108
523-6400
(certified and non-certified agencies)

Division of Health Care Quality
Mass. Department of Public Health
80 Boylston Street
Boston, MA 02116
727-5860
(certified agencies listing--$3.00)

Transportation

- Contact your local transit authority about THE RIDE
- Contact the Registry of Motor Vehicles for handicapped placard and parking plates.
- Inquire about reduced hospital parking tickets from hospital social service departments.
- Special parking permits: the City of Boston has amended its parking ordinance to enable service providers to park in areas designated "residential parking only" during the time service providers are giving therapy to a handicapped child. Boston residents who need parking permits for service providers may call the Commission of Handicapped Affairs at 725-4996.

GAINING ACCESS TO EDUCATIONAL SERVICES

Early Intervention Programs

- Multidisciplinary programs for children 0 - 3 years who are identified as being at established, biological, or environmental risk
- Center-based and home-based services
- For program locations, contact DPH Early Childhood Developmental Services Unit at 727-5089

Head Start

- Free, early childhood program for low-income children ages 3 - 5
- Center-based and home-based services
- Training for parents
- Services to handicapped children in a mainstream setting
- Contact your local community action agency or school department

Special Education (Chapter 766)

- An entitlement program for children ages 3 - 22 who have special needs
- Related services which are identified in the child's Individual Education Plan (IEP) will be provided, including:
  - diagnosis and evaluation
  - audiology
  - counseling and psychological services
  - occupational therapy
  - parent training
  - nursing services

(continued)

- Transportation
- Apply to your local education authority (LEA) otherwise called the special education director, at your local school department

Chapter 688

- A two-year transitional program for severely disabled young adults who will lose their entitlement to special education upon graduation or reaching the age of 22 on or after March 22, 1984.
- A single point of entry into the adult human services system
- The development of an individual transition plan (I.T.P.) for every person found eligible who will need on-going services and support.
- People who are automatically eligible for Chapter 688 services and require no further determination include:
    - those receiving SSI and SSDI based on their own disability
    - anyone listed in the registry of the blind at the Massachusetts Commission for the Blind
- Referrals made through the school system starting at age 20

GAINING ACCESS TO FINANCIAL ASSISTANCE

Federal and State Programs for Health Care

- SSI (Supplemental Security Income)
- Medicaid: through SSI, AFDC or direct Medical Assistance
- Medicare (primarily for the elderly; also serves those with renal disease)
- Hill-Burton Act (free hospital care)
- Department of Public Health: see SHC and MCH
- Little Max: Creating Maximum Benefits for Children, Elderly, Poor and Disabled People. Publication of the Massachusetts Poverty Law Center, 1986.

Local Possibilities for Funding

There are a great number of organizations that raise funds to support the financial, health and social service needs of families with individuals with various disabilities. These include:

- hospitals
- local Associations for Retarded Citizens
- diagnosis-specific organizations (Muscular Dystrophy Association, United Cerebral Palsy, Jimmy Fund, etc.)
- fraternal, business and religious groups

GAINING ACCESS TO MEDICAL SERVICES

The Health Care Team and the Child with a Disability or Chronic Illness

Acute vs. Chronic Illness

Contrast acute illness that many of us have experienced with that of a handicapping condition or chronic illness.

- Acute illness can be very disruptive but generally is contained in a short period.
- A long-term problem means certain things need to be incorporated into one's (and family's) lifestyle. This often results in frequent and intensive relationships with health care providers.
- With acute illness, the goal is frequently to cure. With chronic illness, the goals are management, caring and striving to reach a realistic potential.

The Health Care Team

Selection of health care providers becomes very important. Besides the primary physician, a variety of specialists will probably be needed for diagnosis, planning and implementation of the care plan.

- Primary care provider -- family doctor, pediatrician, PNP
- Specialists -- orthopedist, neurologist, cardiologist, etc.
- Physical therapist
- Occupational therapist
- Nurses
- Social workers
- Nutritionists
- Speech therapists
- Orthotists

(continued)

How to Find Services

If referrals are not made at the time of hospital discharge or you want to investigate a health issue, how do you find these services?

- Ask family doctor
- Talk to other parents
- Call local hospital
- Call Mass. Medical Information for referral (1-800-322-2303)
- Talk to Early Intervention Team
- Talk to school personnel
- Look in the telephone book
- Call Mass. Dept. of Public Health -- Project Serve Directions
- Call the Developmental Evaluation Clinic at:
  - Children's Hospital - Boston
  - Baystate Medical Center - Springfield
  - University of Mass. Medical Center - Worcester

How to Choose Between Providers

- Hospital setting vs. community setting - advantages and disadvantages
- Boston (big city) vs. local - advantages and disadvantages of geographic availability

Parents' Expectations of Health Care Providers

What does the family want in a health care provider?

What can they expect?

(continued)

What can the health care provider offer?

- Individuality: families and providers differ. How to get a good match. A style that is good for one family may not be good for another.
- Respect and sensitivity
- Provide information and interpret medical reports
- Support and help in making decisions
- Respect confidentiality
- Coordination of efforts with other health care providers
- Appropriate referrals
- Advocacy

Frequent Issues

Some issues families deal with:

Frequent change in personnel

- Loss of a certain amount of privacy in getting the help so often needed; it is not natural to have so many people invading your home and life
- Difficult decisions to make; often no clear answers and many tradeoffs
- Financing the care: insurance, Medicaid, HMOs
- Need and appropriateness of second opinions
- Importance of knowing medical history -- having or getting medical record

(continued)

DPH -- Services for Handicapped Children

Philosophical and organizational factors:

- Family-centered
- Encourage family participation
- Close collaboration with others
- Community-based
- Advocacy
- Team approach

FAMILY HEALTH SERVICES TELEPHONE DIRECTORY
LISTINGS
150 TREMONT STREET
BOSTON, MASSACHUSETTS 02111

CENTRAL OFFICE

DIRECTOR'S OFFICE.....(617) 727-3372

ADMINISTRATION SERVICES
- Director of Administration.....(617) 727-6941
  - Budget Unit.....(617) 727-6941
  - Contracts Unit.....(617) 727-6971
  - Fiscal Unit.....(617) 727-6364
- Policy Office.....(617) 727-3372
  - Information and Education.....(617) 727-6436
- Statistics and Evaluation.....(617) 727-6436

SERVICES FOR HANDICAPPED CHILDREN (SHC)
- SHC Director.....(617) 727-5812
- Clinical Services Unit.....(617) 727-5812
- Community Services Unit.....(617) 727-5822
- Early Childhood Development Services Unit.....(617) 727-5089
- Case Management Services Unit.....(617) 727-8925
  (800) 882-1435 (toll-free)

MATERNAL AND CHILD HEALTH SERVICES (MCH)
- MCH Director.....(617) 727-0940
- Primary Care Unit.....(617) 727-0941
- Perinatal and Genetics Unit.....(617) 727-0944
  Genetics Program (617) 727-1246
- Preschool and School Health Unit.....(617) 727-0944
- Women's Health Unit.....(617) 727-1246
- Women, Infants and Children (WIC) Unit.....(617) 727-6876
  (800) WIC-1007 (toll-free)

REGIONAL HEALTH OFFICES

WESTERN REGIONAL HEALTH OFFICE
Northampton Office.....(413) 586-7525
Western Mass. Public Health.....
23 Service Center
Northampton, MA 01060
Pittsfield Office.....(413) 443-4475
246 North Street
Pittsfield, MA 01201

CENTRAL REGIONAL HEALTH OFFICE
Rutland Heights Hospital.....(617) 886-4711 or
Maple Avenue.....(617) 727-1910
Rutland, MA 01543

NORTHEAST REGIONAL HEALTH OFFICE
Tewksbury Hospital.....(617) 851-7261 or
East Street.....(617) 727-7908
Tewksbury, MA 01876

SOUTHEAST REGIONAL HEALTH OFFICE
Lakeville Hospital.....(617) 947-1231 or
Human Services Building.....(617) 727-1440 X 590
Lakeville, MA 02347

BARNSTABLE COUNTY
(SHC Clinic Services are provided under a contract
with the Division of Family Health Services)
Barnstable County Health Department.....(617) 362-2511 X 331
Barnstable County Court House
Barnstable, MA 02360

DPH TOLL-FREE TELEPHONE NUMBERS

AIDS Information Line	1-800-235-2331 (M-F 12-8, Sat. 10-4)
Auto Passenger Safety Resource Center	1-800-CAR-SAFE (M-F 8:45-5)
Lead Poisoning Prevention Program	1-800-532-9571 (M-F 9-4)
Massachusetts Nutrition Resource Center	1-800-322-7203 (M-F 9-4)
Massachusetts Poison Information Center	1-800-682-9211 (7 days, 24 hours)
Patient Abuse Hotline (to report suspected patient abuse/neglect in nursing homes for children and adults)	1-800-462-5540 (M-F 8:45-5) After hours: (617) 522-3700
Pregnancy/Environmental Hotline	1-800-322-5014 (M-F 9-4:30)
SSI (Supplemental Security Income)	1-800-882-1435 (M-F 9-4)
WIC Program	1-800-WIC-1007 (M-F 8:45-5)

The Commonwealth of Massachusetts
Executive Office of Human Services
Department of Public Health
Division of Family Health Services
150 Tremont Street, Boston 02111

CASE MANAGEMENT SERVICES

Staff Listings

Central Office

Mafalda DeSimone, Unit Director
Gail Havelick, Training Specialist

727-8925/26, 1-800-882-1435
150 Tremont Street
Boston, MA 02111

Western Regional Office

(413) 586-7525

Karen Heisey, Supervisor
Jean Day, Case Manager
Marianne Beach, Case Manager
Audrey Kapinos, Secretary

CMSU; DPH Western Region
23 Service Center
Northampton, MA 01060

Pittsfield Office

Kathy Fuchs, Case Manager

(413) 443-4475
246 North Street
Pittsfield, MA 01201

Central Regional Office

727-1910, (617) 886-4711

Bill O'Connell, Supervisor	X324	CMSU; DPH Central Regional Of
Mary Query, Case Manager	X322	Rutland Heights Hospital
Karen Ayers, Case Manager	X323	Maple Avenue
Linda Sweeney, Secretary	X341	Rutland, MA 01543

Northeast Regional Office

727-7908, (617) 851-7261

Denise Guilbeault, Supervisor
Sarah Pentlarge, Case Manager
Eleanor Jacobson, Secretary

CMSU; DPH Northeast Region
Tewksbury Hospital
East Street
Tewksbury, MA 01876

Southeast Regional Office

727-1440, (617) 947-1231

Pauline Monize, Supervisor	X597	CMSU; DPH Southeast Region
Beverly Silva, Case Manager	X596	Lakeville Hospital
Richard Costa, Case Manager	X595	Human Service Building
Nancy Childs, Case Manager	X594	Lakeville, MA 02347
Millie Hogue, Secretary	X535	

Boston Office

727-0747/8

Linda Shepherd, Supervisor
Mary Ellen Delaney, Case Manager
Claire McNulty, Case Manager
Jean Hopkins Sargent, Case Manager
Marie Ceraso, Secretary

CMSU; Boston Office
150 Tremont Street, 4th fl.
Boston, MA 02111

RESOURCE DIRECTORY

COMMONWEALTH OF MASSACHUSETTS OFFICE FOR CHILDREN

HELP FOR CHILDREN REGIONAL OFFICE

CENTRAL OFFICE

20 West Street
Boston, MA 02111
727-8900

REGION I

15 Mulberry Street
Springfield, MA 01105
413-788-8401

REGION II

75-A Grove Street
Worcester, MA 01605
(617)727-8773
(617)791-3136

REGION III

Gregory Street
Middletown, MA 01949
(617)727-8787

REGION IV A

Metropolitan State Hosp.
475 Trapelo Road
Waltham, MA 02154
(617) 727-1429
(617) 891-0530

REGION IV B

425 Watertown Street
Newton, MA 02158
(617) 727-2532

REGION V

Lakeville Hospital
Lakeville, MA 02346
(617)947-1231 ext.607
(617)727-1440

REGION VI

150 Causeway Street
9th floor
Boston, MA 02114
(617) 727-8898

APPEALS PROCESS

Under the law there is an appeals process in place for every agency.

Any person/parent who is dissatisfied with the result of any request has the right to appeal.

Please exercise your right! Many decisions are reversed at the appeal level.

If you are in doubt about your case, please talk to an advocate. Call a Help for Children Regional Office or The Case Management Services of the Department of Public Health.

SOCIAL SECURITY ADMI: S RATION

MASSACHUSETTS DISTRICT OFFICES
ADDRESSES AND PHONE NUMBERS

ATTLEBORO 02703
247 Maple Street
(P.O.Box 2059)
617-222-0273

BOSTON 02114
10 Causeway Street

617-227-2400

BROCKTON 02401
Westgate Mall-166 Main St.
617-588-7835

BROOKLINE 02146
1309 Beacon Street
617-227-2400

SOMERVILLE 02144
240 Elm Street
P.O.BOX 310

617-227-2400 (Gr. Boston)

CHELSEA 02150
166 Everett Avenue
Mystic Mall-166 Everett Ave.
617-227-2400

DORCHESTER 02122
540 Gallivan Boulevard
617-227-2400

FALL RIVER 02720
400 North Main Street
617-676-1981

FALMOUTH 02540
344A Gifford Street
(P.O. Box 667)
627-548-8150

FITCHBURG 01420
881 Main Street Room 305
617-345-1812

FRAMINGHAM 01701
216 Howard Street
617-875-6191

GARDNER 01440
55 Lake Street
617-632-7432

GREENFIELD 01301
11 Davis Street
413-773-7327

HANOVER 02339
198 Columbia Road
617-826-6383

HAVERHILL 01830
367 Main Street
617-374-1968

HOLYOKE 01040
302 High Street
413-534-7361

HYANNIS 02601
181 Walton Avenue
617-775-7501

LAWRENCE 01840
229 Essex Street
617-686-6171

LOWELL 01852
26 Palmer Street
617-454-9151

LYNN 01901
140 Union Street
617-581-7460 (local)
617-227-2400 (Gr. Boston)

MALDEN 01248
200 Pleasant Street
617-322-0884
617-227-2400 (Gr. Boston)

NEW BEDFORD 02740
53 North 6th Street
P.O. Box H-3104
617-999-3197

NORTH ADAMS 01247
106 Main Street
413-663-5327

NORWOOD 02062
480 Washington Street
617-762-7000

PITTSFIELD 01201
78 Center Street
413-445-4582

QUINCY 02169
191 Parkingway
617-227-2400

ROSLINDALE 02131
33 Corinth Street
617-227-2400

ROXBURY 02119
2315 Washington Street
617-227-2400

SALEM 01970
1 East India Square
617 744-2366

SPRINGFIELD 01103
1550 Main Street (Federal Bu
413-785-0000

TAUNTON 02780
19 Court Street
617-823-5116

WALTHAM 02154
50 Prospect Street
617-893-0141

WORCESTER
25 High Street
617-793-0430

WOONSOCKET R.I. 02895
Stadium Building Room 218
401-767-2100

Revised 10/87

HANDICAP PLATE/HANDICAP PLACARD APPLICATION
MASSACHUSETTS REGISTRY OF M TOR VEHI LES
100 NASHUA STREET, BOSTON 02114
727-3865

APPLICANTS ARE ENTITLED TO ONLY ONE SET OF HANDICAP PLATES OR ONE PLACARD

INSTRUCTIONS: The applicant should fill out Part A of this form, then submit Part B to his/her attending physician for completion and signature. The applicant must then return the fully completed form the Medical Affairs Section of the Registry of Motor Vehicles the enclosed envelope.

****

PART A

PLEASE CHECK PROPER BOX: HP PLATES ☐ HP PLACARD ☐

APPLICANT INFORMATION (PLEASE PRINT CLEARLY OR TYP

1. NAME: _____
(LAST) (FIRST) (MIDDLE)

2. ADDRESS: _____
(STREET) (CITY/TOWN) (ZIP)

3. DATE OF BIRTH: _____
(MONTH) (DAY) (YEAR)

4. DRIVER'S LICENSE #: _____ CLASS _____ EXPIRES _____

5. TELEPHONE #: HOME _____ WORK _____

6. RESTRICTIONS ON LICENSE, IF ANY: _____

_____

****

IF YOU POSSESS A VALID OPERATORS LICENSE AND HAVE NOT BEEN TESTED FOR HANDI(STATED, A COMPETENCY ROAD TEST WILL BE REQUIRED AS PART OF YOUR EVALUATIOI

****

7. PERSON(S) TO WHOM VEHICLE IS PRESENTLY REGISTERED _____

IF HANDICAP PERSON DOES NOT POSSESS AN OPERATORS LICENSE, PLEASE COMPLETE THE FOLLOWING:

8. NAME OF PRINCIPAL OPERATOR: _____

DRIVER'S LICENSE #: _____ CLASS: _____ EXPIRES: _____

TELEPHONE #: HOME _____ WORK _____

****

UPON COMPLETION OF "PART A", SUBMIT THIS FORM TO YOUR PHYSICIAN TO COMPLETE "PART B" BEFORE FORWARDING TO THE REGISTRY OF MOTOR VEHICLES

****

- FOR OFFICE USE ONLY - CATEGORY CODE ____

APPROVED ☐ NOT APPROVED ☐ FOR: HP PLATES ☐ HP PLACARD

_____ _____
(DATE) (SUPERVISOR'S SIGNATURE)

MAR-Rev. 4 2-7-86

PART B PHYSICIAN'S QUESTIONNAIRE

PLEASE NOTE: Approval of Handicap Plates or Placard for your patient is based upon information provided by you. Therefore, it is important to submit all pertinent Medical Facts relative to the Applicant's Disability.

ATTENDING PHYSICIAN'S NAME: _____
ADDRESS: _____ TEL. # _____

A. DATE OF LAST PHYSICAL EXAMINATION _____

B. NATURE OF HANDICAP _____

C. IS THIS HANDICAP: PERMANENT ☐ TEMPORARY ☐

D. PLEASE NOTE WHICH, IF ANY, OF THE FOLLOWING HANDICAPS IS ATTRIBUTABLE TO THE APPLICANT:

1. LOSS OF, OR PERMANENT LOSS OF USE OF ONE OR BOTH FEET ☐
   (Please Describe) _____

2. LOSS OF, OR PERMANENT LOSS OF USE OF ONE OR BOTH HANDS ☐
   (Please Describe) _____

3. DECLARED LEGALLY BLIND: YES ☐ NO ☐
   (Please attach copy of certification)

4. EXTREMELY UNFAVORABLE COMPLETE ANKLYOSIS OF THE KNEE ☐

5. COMPLETE ANKLYOSIS OF TWO (2) MAJOR JOINTS OF A LOWER EXTREMITY

6. SHORTENING OF THE LOWER EXTREMITY OF THREE-AND-ONE HALF INCHES, (3½ inches or more) ☐

7. COMPLETE PARALYSIS OF THE EXTERNAL POPLITEAL NERVE (COMMON PERONEAL) AND CONSEQUENT FOOT DROP ACCOMPANIED BY CHARACTERISTIC ORGANIC CHANGES, INCLUDING TROPHIC AND CIRCULATORY DISTURBANCE. ☐

8. CHRONIC RENAL FAILURE REQUIRING REGULAR DIALYSIS ☐

9. CHRONIC LUNG DISEASE (Complete Information Requested Below) ☐

   Fev-1 Test Results (Litres or CC:) _____

   Is Oxygen Therapy Prescribed? YES ☐ NO ☐
   (If YES, please describe), _____

10. CHRONIC HEART DISEASE (a copy of patients functional and therapeutic classification under the American Heart Association guidelines must be submitted). ☐

E. PRESCRIBED PERMANENT AMBULATORY AIDS USED: YES ☐ NO ☐

(If YES, please describe) _____

ATTENDING PHYSICIAN'S SIGNATURE _____
REGISTRATION NUMBER _____

IF YOU WISH TO PROVIDE FURTHER MEDICAL INFORMATION REGARDING THE APPLICANT'S DISABILITY PLEASE FEEL FREE TO SUBMIT AN ACCOMPANYING LETTER WITH THIS APPLICATION.

QUESTIONS AND ANSWERS ABOUT THE HP "PLACARD"

1. Q. WHAT IS AN HP PLACARD?

   A. It is a special identification card authorized by the Registry, bearing the international handicapped symbol and an assigned I.D. number on the front. In addition, the handicapped person's photograph and name are on the back of the placard.

2. Q. WHO MAY BE ELIGIBLE FOR THIS SPECIAL PLACARD?

   A. Any handicapped person — child or adult — who qualifies under the Registry's Medical Affairs section's guidelines.

3. Q. CAN I HAVE HP PLATES AND A HP PLACARD AT THE SAME TIME?

   A. No. You may choose to have one or the other.

4. Q. WHAT IS THE BENEFIT OF THE PLACARD?

   A. The placard is transferable from one passenger vehicle to another.

5. Q. HOW DO I APPLY FOR A HP PLACARD?

   A. The same as you would for HP plates. Anyone may pick up an application at any Registry branch office, or call and request that an application be mailed.

6. Q. ARE THE QUALIFICATION STANDARDS THE SAME FOR THE HP PLACARD AS THEY ARE FOR HP PLATES?

   A. Yes.

7. Q. HOW MUCH WILL IT COST FOR THE PLACARD?

   A. Because a fee has not been authorized, there is no charge at this time.

8. Q. ONCE I RECEIVE THE PLACARD, WHAT DO I DO WITH IT?

   A. The placard must be visible through the left portion of the windshield of a private passenger vehicle.

9. Q. CAN ANYONE ELSE USE MY PLACARD?

   A. No. Only the person whose number and photograph are displayed on the back of the placard.

10. Q. IS THERE A PENALTY FOR MISUSE?

    A. Yes. Anyone other than the authorized bearer who uses a parking I.D. placard in a motor vehicle will be subject to a fine of $100.

(OVER)

11. Q. WHAT HAPPENS TO MY HP PLACARD IF IT IS USED BY ANOTHER PERSON?

A. Use of the placard by any person other than the bearer may be cause for revocation of the placard.

12. Q. WHO DETERMINES ELIGIBILITY FOR HP PLATES OR THE HP PLACARD?

A. The Registry's Medical Advisory Board.

13. Q. CAN I PARK ANYWHERE I WANT WITH HP PLATES OR THE HP PLACARD?

A. No. Violating the rules and regulations which prohibit parking or standing may call for removal of the vehicle, storage of said vehicle, and/or a possible fine.

14. Q. CAN I USE MY HP PLATES OR HP PLACARD ON ANY VEHICLE?

A. No. HP plates or a HP placard can only be used on private passenger vehicles.

15. Q. CAN I LEAVE MY HP PLACARD IN THE WINDSHIELD OF A VEHICLE EVEN IF IT IS NOT BEING USED FOR MY TRANSPORTATION ON ANY GIVEN DAY?

A. No. The HP placard must be removed from the windshield when you have finished traveling for the day.

16. Q. WHO MAY PARK IN A HANDICAPPED PARKING SPACE?

A. Any disabled veteran or handicapped person whose vehicle bears the HP number plates or displays the special parking identification placard issued by the Registry. Official handicapped plates issued by other states are also acceptable for visitors.

17. Q. CAN HP PLATES OR HP PLACARDS BE ISSUED TO OTHER THAN THE HANDICAPPED PERSON, SUCH AS TO A VAN OR BUS USED TO TRANSPORT THE HANDICAPPED?

A. No. The law clearly states that a private passenger vehicle must be owned or leased by the handicapped person. However, the HP placard may be issued to an individual who is not licensed to drive, does not own a vehicle, or prefers the flexibility of a placard.

The Commonwealth of Massachusetts
Executive Office of Human Services
Department of Public Health
Division of Family Health Services
150 Tremont Street, Boston 02111

Deborah Prothrow-Stith, M.D.
Commissioner

Re:

Disposable diapers are Medicaid approved (with prior approval) if the steps below are followed:

1. Have your pediatrician send a letter (to address below) stating the child's diagnosis, and that disposable diapers are a medical necessity because of incontinence. Include the amount needed, (one case per month usually suffices), and the name and address of the pharmacy. The child's name, address, date of birth and Medicaid number must be included.

2. The doctor will receive a letter back with a prior approval number. This number must be put on the prescription, for without it the pharmacy cannot fill the order.

3. If, after two weeks you have not received your prescription, be sure to call doctor's office to check on the status of your diaper request.

4. The prescription is good for six months at a time. You must remind your doctor's office at the end of five and one-half months that the prescription needs to be renewed. The physician must then repeat the procedure. There should be no interruption of services if these instructions are followed.

Letters are sent to one of the following locations:

(ALL OTHER CHILDREN)

Department of Public Welfare
Medical Pharmacy, Room #740
600 Washington Street
Boston, MA 02111

(If the child is enrolled with the COMMISSION FOR THE BLIND)

Mass. Commission for the Blind
Medical Assistance
110 Tremont Street
Boston, MA 02108

Please call if there are any questions.

Sincerely,

Case Management Services Unit

CMSU-12/86

The Commonwealth of Massachusetts
Department of Public Health
SOUTHEASTERN REGIONAL OFFICE
LAKEVILLE HOSPITAL
LAKEVILLE 02347

Commissioner

Tel: 947-1231 X589/5
727-1440

HOSPITAL PARKING TICKETS

Low income parents who must take their child to Children's Hospital Medical Center in Boston on a frequent basis are able to get reduced rate, parking garage tickets by doing the following:

1. Go to the Special Services Office in Gardner House (across from the Emergency Room).

2. Explain situation (frequent trips to hospital because child is disabled, low income, etc.).

3. Reduced rate tickets will be issued at a cost of $2.50 each.

4. If any problems arise, see the Social Service worker at Children's Hospital.

Pauline Monize

Pauline E. Monize, Supervisor
Case Management Services Unit
Division of Family Health Services
Services For Handicapped Children

MISCELLANEOUS INFORMATION REGARDING MEDICAID PAYMENT

o TRANSPORTATION

Transportation of the patient to any approved medical facility, clinic, doctor's office, treatment facility, etc. is provided under Medicaid. By calling the Medicaid Transportation person in your local Dept. of Public Welfare you can be approved for ambulance, travel chair car, taxi or if you use your own vehicle you can be reimbursed at the rate of 22¢ per mile. A friend's car also qualifies.

Be sure that you get proof from the medical provider that you have received services. Further, if a parent visits a hospital for purpose of training or medical conference, transportation is certifiable.

Medicaid reimbursement is retroactive for the entire fiscal year.

o FUNERAL EXPENSES

The Dept. of Public Welfare may pay a sum not exceeding $1,100 for funeral and burial expenses of a recipient providing that the total cost of the funeral and burial does not exceed $1,500. If the cost is higher that $1,500 the department will pay nothing.

o HILL BURTON ACT

Apply at local hospital. Not every facility participates in the Hill Burton Act, but usually each city will have such a facility

Free care (in hospital). Some hospitals, clinics, health care facilities may be required by law to:

Provide emergency treatment to those who meet the financial criteria, are unable to pay and carry no other form of medical insurance.

RECREATION RESOURCES

Sports and Recreation

General Information:

Information Center for Individuals with Disabilities (ICID)
20 Park Plaza, Room 330
Boston, MA 02116
Phone: (617) 727-5540/Voice;
(617) 727-5236/TTY; 1-800-462-5015
ICID is an excellent source of information for families. ICID publishes "fact sheets" on many different topics, including recreation. The following are especially useful:

- Recreation Organizations and opportunities for Disabled Individuals - comprehensive list of local and national organizations, covering 36 different sports, games, and activities
- Swimming Resources for Individuals with Disabilities-Greater Boston Area
- Horseback Riding Programs in New England and New York for People with Disabilities
- Accessible Overnight Campgrounds - Massachusetts
- Accessible Nature Trails - Massachusetts

Massachusetts Association for Retarded Citizens (ARC)
217 South Street
Waltham, MA 02154
Phone: (617) 891-6270
Contact Person: Judy Weintraub
There are almost 30 ARC's throughout the state, and programs vary. Contact the state office above, to get the name and number of your local ARC

Massachusetts Special Olympics Program
P.O. Box 303
Hathorne, MA 01937
Phone: (617) 774-1501
Contact this office for a calendar of events and schedule of the winter, spring and summer games, or a referral to your area coordinator.

Project Adventure, Inc.
P.O. Box 100
Hamilton, MA 01936
Phone: (617) 468-7981
Contact Person: Bonnie Frye
A non-profit national organization which trains teachers, parents, and others who work with children to carry out different Project Adventure programs in their own schools.

Jewish Community Center of Greater Boston
333 Nahantan Street
Newton, MA 02159
Phone: (617) 965-7410X279; Director of Special Needs Services

Arts/Music

Very Special Arts, Massachusetts
59 Temple Place
Boston, MA 02114
Phone: (617) 350-7713 or Daniel Wein
VSA Program Coordinator
Massachusetts Department of Education
1385 Hancock Street
Quincy, MA 02169
Phone: (617) 770-7489
VSA is a part of a national program in the arts.

Center for Creative Art Therapies (CCAT)
731 Harrison Avenue
Boston, MA 02118
Phone: (617) 262-6183
Contact Person: Ricky Stern, Directo
CCAT is staffed by eight clinically-trained art, dance, and music therapists.

Community Music Center of Boston (CMC
48 Warren Avenue
Boston, MA 02116
Phone: (617) 482-7494
Contact Person: Karen Wax, Music Therapy Coordinator
The (CMC) provides individual instruction as well as outreach services in many different settings around the Boston area by qualified Music Therapists.

All-Newton Music School
321 Chestnut Street
West Newton, MA 02165
Phone: (617) 527-4553
All-Newton provides private lessons by a Music Therapist for children with special needs.

Taken from: THE EXCEPTIONAL PARENT Vol. 17 #6, September 1987

American Diabetes Association
National Service Center
1660 Duke St
Alexandria, Va. 22314
(703) 549-1500
(800) 232-3472

American Foundation for the Blind
15 W. 16th St.
New York, N.Y. 10011
(212) 620-2000

American Heart Association
7320 Greenville Ave.
Dallas, Texas 75231
(214) 750-5300

American Juvenile Arthritis Organization (AJAO)
1314 Spring St. N.W.
Atlanta, Ga. 30309
(404) 872-7100

American Kidney Fund
6110 Executive Blvd.
Suite 1010
Rockville, Md. 20852
(800) 638-8299

American Lung Association
1740 Broadway
New York, N.Y 10019
(212) 315-8700

American Lupus Society
23751 Madison St.
Torrance, Calif. 90505
(213) 373-1335

American Printing House for the Blind
1839 Frankfort Ave.
P O. Box 6085
Louisville, Ky. 40206
(502) 895-2405

American Society for Deaf Children (ASDC)
814 Thayer Ave.
Silver Spring, Md. 20910
(301) 585-5400

American Tuberous Sclerosis Association
P.O. Box 1305
Middleboro, Mass. 02346
(617) 947-8893
(800) 446-1211

Associated Services for the Blind
919 Walnut St.
Philadelphia, Pa. 19107
(215) 627-0600

Association for Children with Down Syndrome
2616 Martin Ave.
Bellmore, N.Y. 11710
(516) 221-4700

Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburgh, Pa. 15234
(412) 341-1515
(412) 341-8077

Association for Retarded Citizens of the U.S.
2501 Avenue J
Arlington, Texas 76011
(817) 640-0204
(800) 433-5255

Association of Birth Defect Children
3526 Emerywood Lane
Orlando, Fla. 32806
(305) 859-2821

Asthma and Allergy Foundation of America
1717 Massachusetts Ave.N.W.
Suite 305
Washington, D.C. 20036
202) 265-0265

Better Hearing Institute Hearing Helpline
P.O. Box 1840
Washington, D.C. 20013
(800) 424-8576

Canadian Cerebral Palsy Association
40 Duncas St. W.
Suite 222, P.O. Box 110
Toronto, Ont.
Canada M5G 2C2
(416) 979-7923

Canadian Association for Community Living
(Mental retardation)
Roeher Institute
Kingsmen Building
York University
4700 Keele St.
Downsview, Ont.
Canada M3J 1P3
(416) 661-9611

Canadian Diabetes Association
78 Bond St.
Toronto, Ont.
Canada M5B 2J8
(416) 362-4440

Canadian Hearing Society
271 Spadina Road
Toronto, Ont.
Canada M5R 2V3
(416) 964-9595 (Voice)
(416) 964-2066 (TDD)

Canadian Hemophilia Society
100 King St. W., Suite 210
Hamilton, Ont.
Canada L8P 1A2
(416) 523-6214

Canadian National Institute for the Blind
1929 Bayview Ave.
Toronto, Ont.
Canada M4G 3E8
(416) 486-2500

Cancer Information Clearinghouse
National Cancer Institute
9000 Rockefeller Pike
Bethesda, Md. 20205
(800) 638-6694

Candlelighters Childhood Cancer Foundation
2025 Eye St. N.W.
Suite 1011
Washington, D.C. 20006
(202) 659-5136

Caring Inc.
(Down syndrome)
P.O. Box 400
Milton, Wash. 98354
(206) 922-8194

Children's Brain Diseases Foundation for Research
350 Parnassus, Suite 900
San Francisco, Calif. 94117
(415) 566-5402
(415) 566-6259

Children's Hearing Foundation
220 S 16th St.
Philadelphia, Pa. 19102

Children's Liver Foundation
7 Highland Place
Maplewood, N.J. 07040
(201) 761-1111

CMT International
(Charcot-Marie-Tooth Disease)
34 Bayview Drive
St. Catharines, Ont.
Canada L2N 4Y6
(416) 937-3851

Compassionate Friends
(child has died)
Box 3696
Oak Brook, Ill. 60522-3696
(312) 990-0010

Cornelia de Lange Syndrome Foundation
60 Dyer Ave.
Collinsville, Conn. 06022
(203) 693-0159
(800) 223-8355

Cri du Chat
(Cat Cry syndrome)
The 5p- Society
11609 Oakmont
Overland Park, Kan. 66210
(913) 469-8900

Cystic Fibrosis Foundation
6931 Arlington Road
Bethesda, Md. 20814-5205
(301) 951-4422
(800) FIGHT CF

Deafpride
2010 Rhode Island Ave. N.E.
Washington, D.C. 20018
(202) 635-2050

Digestive Diseases Clearinghouse
1255 23rd St. N.W. #275
Washington, D.C. 20037
(202) 296-1138

Dysauntonomia Foundation
370 Lexington Ave., Room 1504
New York, N.Y. 10017
(212) 889-5222

Dystonia Medical Research Foundation
First City Bldg., Suite 1800
777 Hornby St.
Vancouver, B.C.
Canada V6Z 1S4
(604) 661-4886

Dystonia Medical Research Foundation
8383 Wilshire Blvd., Suite 800
Beverly Hills, Calif. 90211
(213) 852-1630

Dystrophic Epidermolysis Bullosa Research Association of America, Inc.
Kings County Medical Center
451 Clarkson Ave.
Brooklyn, N.Y. 11203
(718) 774-8700

Epilepsy Foundation of America (EFA)
4351 Garden City Drive
Landover, Md. 20785
(301) 459-3700

Families of Spinal Muscular Atrophy (SMA)
P.O. Box 1465
Highland Park, Ill. 60035
(312) 432-5551

Families of Children Under Stress (FOCUS)
P.O. Box 1058
Conyers, Ga. 30207
(404) 483-9845

Foundation for Children with Learning Disabilities
P.O. Box 2929
Grand Central Station
New York, N.Y. 10016
(212) 687-7211

Fragile X Foundation
P.O. Box 300233
Denver, Colo. 80203
(800) 835-2246 ext. 58

Friedreich's Ataxia Group in America
P.O. Box 11116
Oakland, Calif. 94611
(415) 655-0833

Guardians of Hydrocephalus Research Foundation
2618 Avenue Z
Brooklyn, N.Y. 11235
(718) 743-4473

Help for Incontinent People (HIP)
P.O. Box 544
Union, S.C. 29379
(803) 585-8789

Hydrocephalus Support Group
225 Dickinson St., H-893
San Diego, Calif. 92103
(619) 726-0507
(619) 583-4096

Immune Deficiency Foundation (IDF)
P.O. Box 586
Columbia, Md. 21045
(301) 461-3127

International Rett Syndrome Association
8511 Rose Marie Drive
Fort Washington, Md. 20744
(301) 248-7031

International Shriners Headquarters
(orthopedic and burn injuries)
P.O. Box 25356
Tampa, Fla. 33622
(800) 237-5055

Intraventricular Hemorrhage Parents
P.O. Box 56-1111
Miami, Fla. 33156
(305) 232-0381

Juvenile Diabetes Foundation International
423 Park Ave. S.
New York, N.Y. 10016-8013
(212) 889-7575
(800) 223-1138

Laurence-Moon-Biedl Syndrome Network
122 Rolling Road
Lexington Park, Md. 20653
(301) 863-5658

Leukemia Society of America
733 Third Ave., 14th floor
New York, N.Y. 10017
(212) 573-8484

Little People of America
P.O. Box 633
San Bruno, Calif. 94066
(415) 589-0695

Lowe's Syndrome Association
222 Lincoln St.
West Lafayette, Ind. 47906
(317) 743-3634

Lupus Foundation of America
1717 Massachusetts Ave
N.W., Suite 203
Washington, D.C. 20036
(800) 558-0121

Maple Syrup Urine Disease Family Support Group
24806 SR 119
Goshen, Ind. 46526
(219) 862-2992

Maple Syrup Urine Disease Family Support Group
RR 2 Box 24A
Flemingsburg, Ky. 41041
(606) 849-4679

Metabolic Illness Foundation
210 S. Fourth St.
Monroe, La. 71202
(318) 343-0416

Muscular Dystrophy Association
810 Seventh Ave.
New York, N.Y. 10019
(212) 586-0808

National Amputation Foundation
12-45 150th St.
Whitestone, N.Y. 11357
(718) 767-0596

National Association for Hearing and Speech Action (NAHSA)
10801 Rockville Pike
Rockville, Md. 20852
(301) 897-8682
(800) 638-8255

National Association for Parents of the Visually Impaired
P.O. Box 180806
Austin, Texas 78718
(512) 323-5710

National Association for Sickle Cell Disease (NASCD)
4221 Wilshire Blvd., Suite 360
Los Angeles, Calif. 90010-3503
(213) 936-7205
(800) 421-8453

National Association for Visually Handicapped
22 W. 21st St., Sixth floor
New York, N.Y. 10010
(212) 889-3141

National Association of the Deaf (NAD)
814 Thayer
Silver Spring, Md. 20910
(310) 587-1788

National Ataxia Foundation
600 Twelve Oaks Center
15500 Wayzata Blvd
Wayzata, Minn. 55391
(612) 473-7666

National Autism Hotline
Autism Services Center
Douglas Education Bldg.
10th Avenue & Bruce
Huntington, W Va 25701
(304) 525-8014

National Captioning Institute
5203 Leesburg Pike
Falls Church, Va. 22041
(703) 998-2400
(800) 528-6600

National Center for Stuttering
200 E. 33rd St.
New York, N.Y. 10016
(212) 532-1460
(800) 221-2483

National Center for the Prevention of Sudden Infant Death Syndrome
330 N. Charles St.
Baltimore, Md. 21201
(800) 638-7437

National Down Syndrome Congress
1800 Dempster St.
Park Ridge, Ill. 60068-1146
(312) 823-7550
(800) 232-6372

National Down Syndrome Society
141 Fifth Ave., Seventh Floor
New York, N.Y. 10010
(212) 460-9330
(800) 221-4602

National Federation of the Blind
1800 Johnson St.
Baltimore, Md. 21230
(301) 659-9314

National Mucopolysaccharidoses Society
17 Kraemer St.
Hicksville, N.Y. 11801
(516) 931-6338

National Multiple Sclerosis Society
205 E. 42nd St.
New York, N.Y. 10017
(212) 986-3240
(800) 822-3379

National Neurofibromatosis Foundation, Inc.
141 Fifth Ave., Suite 7-S
New York, N.Y. 10010
(212) 460-8980

National Organization for Albinism and Hypopigmentation
4721 Pine St.
Philadelphia, Pa. 19143
(215) 627-0600

National Organization for Rare Disorders
P.O. Box 8923
New Fairfield, Conn. 06812
(203) 746-6518

National Reye's Syndrome Foundation
426 N. Lewis
Bryan, Ohio 43506
(419) 636-2679

National Hemophilia Foundation (NHF)
110 Greene St., Room 406
New York, N.Y. 10012
(212) 219-8180

National Hydrocephalus Foundation
Route 1, River Road, Box 210A
Joliet, Ill. 60436
(815) 467-6548

National Icthyosis Foundation
P.O. Box 252
Belmont, Calif. 94002
(415) 591-1653

National Information Center on Deafness
Gallaudet University
800 Florida Ave. N.E.
Washington, D.C. 20002
(202) 651-5051 (Voice)
(202) 651-5052 (TDD)

National Institute of Dyslexia
3200 Woodbine St.
Chevy Chase, Md. 20815
(301) 652-0942

National Kidney Foundation
2 Park Ave.
New York, N.Y. 10016
(212) 889-2210

National Foundation for Asthma
P.O. Box 30069
Tucson, Ariz. 85751-0069
(602) 323-6046

National Foundation for Facial Reconstruction
550 First Ave.
New York, N.Y. 10016
(212) 340-6656

National Foundation for Ileitis and Colitis
444 Park Ave. S.
New York, N.Y. 10016
(212) 685-3440

National Foundation for Peroneal Muscular Atrophy
University City Science Center
3624 Market St.
Philadelphia, Pa. 19104
(215) 387-2255

National Head Injury Foundation
P.O. Box 567
Framingham, Mass. 01701
(617) 879-7473

National Hearing Aid Society
20361 Middlebelt
Livonia, Mich. 48152
(313) 478-2610
(800) 521-5247

National Scoliosis Foundation
P.O. Box 547
93 Concord Ave.
Belmont, Mass. 02178
(617) 489-0888/0880

National Sickle Cell Clinics Foundation
P.O. Box 8095
Houston, Texas 77288
(713) 651-8071

National Society for Children and Adults with Autism
1234 Massachusetts Ave.
N.W., Suite 1017
Washington, D.C. 20005
(202) 783-0125

National Society to Prevent Blindness
500 E. Remington Road
Schaumburg, Ill. 60173
(312) 843-2020

National Spinal Cord Injury Association
149 California St.
Newton, Mass. 02158
(617) 964-0521
(800) 962-9629

National Spinal Cord Injury Hotline
2201 Argonne Drive
Baltimore, Md. 21218
(800) 526-3456

National Stuttering Project
1269 Seventh Ave
San Francisco, Calif 94122
(415) 566-5324

National Sudden Infant Death Syndrome (SIDS) Foundation
8200 Professional Place
Suite 104
Landover, Md. 20785
(301) 459-3388
(800) 221-SIDS

National Tay-Sachs and Allied Diseases Assn.
385 Elliot St.
Newton, Mass. 02164
(617) 964-5508

National Technical Institute for the Deaf
at Rochester Institute
One Lomb Memorial Drive
P.O. Box 9887
Rochester, N.Y. 14623
(716) 475-6400

National Tuberous Sclerosis Association
P.O. Box 612
Winfield, Ill 60190
(312) 668-0787

Orton Dyslexia Society
724 York Road.
Baltimore, Md. 21204
(301) 296-0232
(800) 222-3123

Osteogenesis Imperfecta Foundation
P.O. Box 245
Eastport, N.Y. 11941
(516) 325-8992

Paralyzed Veterans of America
801 18th St. N.W.
Washington, D.C. 20006
(202) 872-1300

Parents of Cataract Kids
179 Hunter's Lane
Devon, Pa. 19333
(215) 293-1917
(215) 721-9131

Parents of Dwarfed Children
11524 Colt Terrace
Silver Spring, Md. 20902
(301) 649-3275

Parents of John Tracy Clinic
(hearing impairment)
806 W. Adams Blvd.
Los Angeles, Calif. 90007
(213) 748-5481

Prader-Willi Syndrome Association
5515 Malibu Drive
Edina, Minn. 55436
(612) 933-0113

Prescription Parents
(cleft palate)
P.O. Box 426
Quincy, Mass. 02269
(617) 479-2463

Retinitis Pigmentosa (RP) Association International
P.O. Box 900
Woodland Hills, Calif. 91365
(818) 992-0500
(800) 344-4877

RP Foundation Fighting Blindness
1401 Mt. Royal Ave. 4th Floor
Baltimore, Md. 21217
(301) 225-9400
(800) 638-2300

Self Help for Hard of Hearing People (SHHH)
7800 Wisconsin Ave.
Bethesda, Md. 20814
(301) 657-2248

SEE Center for the Advancement of Deaf Children
P.O. Box 1181
Los Alamitos, Calif. 90720
(213) 430-1467

Speech Foundation of America
P.O. Box 11749
Memphis, Tenn. 38111
(800) 992-9392

Spina Bifida Association of America
1700 Rockville Pike #540
Rockville, Md. 20852-1631
(301) 770-7222
(800) 621-3141

Spina Bifida Association of Canada
633 Wellington Crescent
Winnipeg, Manitoba
Canada R3M 0A8
(204) 452-7580

Support Organization for Trisomy 18/13
c/o Kris and Hal Holladay
1522 E. Garnet
Mesa, Ariz. 85204-5957
(801) 882-6635

Tourette Syndrome Assn.
2001 Ford Circle, Suite G
Milford, Ohio 45150-2713
(513) 831-2976
(513) 543-2675

Tripod-Service for the Hearing Impaired
955 N. Alfred St.
Los Angeles, Calif. 90069
(213) 656-4904
(800) 352-8888

Turner's Syndrome Society
4700 Keele St.York University
Downsview, Ont.
Canada M3J 1P3
(416) 736-5023

United Cerebral Palsy Association
66 E. 34th St.
New York, N.Y. 10016
(212) 481-6300
(800) USA-1UCP

United Leukodystrophy Foundation
2304 Highland Drive
Sycamore, Ill. 60178
(815) 895-3211

United Ostomy Association
36 Executive Park, Suite 120
Irvine, Calif. 92714
(714) 660-8624

Williams Syndrome Association
P.O. Box 178373
San Diego, Calif. 92117-0910
(713) 376-1626

PARENT COALITION GROUPS

Advocacy Center for Children's Education and Parent Training
P.O. Box 10565
Raleigh, N.C. 27605
(919) 821-2048

Advocacy, Inc.
7700 Chevy Chase, Suite 300
Austin, Texas 78752
(512) 454-4816

Arkansas Coalition for the Handicapped
519 E. Fifth St.
Little Rock, Ariz. 72402
(501) 376-0378

Asociacion de Padres Pro Beinstar de Ninos Impedidos de Puerto Rico, Inc. (APNI)
Box 21301
Rio Piedras, P.R. 00928
(809) 765-0345
(809) 763-4665

Association for Retarded Citizens/Allegheny
1001 Brighton Road
Pittsburgh, Pa. 15233
(412) 322-6008

Association for Retarded Citizens of North Carolina
Family and Infant Pre-School Program
Western Carolina Center
300 Enola Road
Morganton, N.C. 28655
(704) 433-2661

Association for Retarded Citizens of Texas
833 Houston St.
Austin, Texas 78756
(512) 454-6694

Association of Developmental Organizations of Mississippi
6055 Highway 18 S., Suite A
Jackson, Miss. 39209
(601) 922-3210

Broader Opportunities for the Learning Disabled (BOLD)
P.O. Box 546309
Surfside, Fla. 33154
(305) 866-3262

Citizens Alliance to Uphold Special Education (CAUSE)
Parents Training Parent Program
313 S. Washington St.
Suite 040
Lansing, Mich. 48933
(517) 485-4084

Coalition in Oregon for Parent Education (COPE)
999 Locust St. N.E. #42
Salem, Ore. 97303
(503) 373-7477

Connecticut Parent Advocacy Center
Mohegan Community College
Mahan Drive
Norwich, Conn. 06360
(203) 886-5250

Coordinating Council for Handicapped Children
20 E. Jackson, Room 900
Chicago, Ill. 60604
(312) 939-3513 (Voice)
(312) 939-3519 (TDD)

Denver Association for Retarded Citizens
899 Logan, Suite 311
Denver, Colo. 80203
(303) 831-7733

Designs for Change
220 S. State St., Suite 1900
Room 1616
Chicago, Ill. 60604
(312) 922-0317

Each, Inc.
P.O. Box 121257
Nashville, Tenn. 37212
(615) 298-1080

Exceptional Children's Advocacy Council
P.O. Box 16
Davidson, N.C. 28036
(704) 892-1321

Families of Children Under Stress (Focus, Inc.)
2917 King St., Suite C
Jonesboro, Ariz. 72401
(501) 935-2750

Families Together
Box 86153
Topeka, Kan. 66686
(913) 273-6343

Federation for Children with Special Needs
312 Stuart St., Second Floor
Boston, Mass. 02116
(617) 482-2915

Involve New Jersey, Inc.
26-CZ E. Second St.
Moorestown, N.J. 08057
(609) 778-0599

Iowa Pilot Parents
1602 10th Ave. N.
P.O. Box 1151
Ft. Dodge, Iowa 50501
(515) 576-5870

Kentucky Coalition for Career and Leisure Development
366 Waller Ave., Suite 119
Lexington, Ky. 40504
(606) 278-4712

Keshet
Jewish Parents of Children with Special Needs
P.O. Box 59065
Chicago, Ill. 60645
(312) 588-0551

Maine Parent Federation
P.O. Box 2067
Augusta, Maine 04330
(207) 767-3101

Multicultural Impact, Inc.
University Affiliated Program
Children's Hospital of Los Angeles
P.O. Box 54700
Los Angeles, Calif. 90054
(213) 669-2300

National Parent CHAIN
90 E. Wilson Bridge Rd.
Suite 297
Worthington, Ohio 43085
(614) 431-1911 (Voice and TDD)

Nevada Association for the Handicapped
6200 W. Oakey Blvd.
Las Vegas, Nev. 89102-1142
(702) 870-7050

New Hampshire Coalition for Handicapped Citizens
Parent Information Center
P.O. Box 1422
Concord, N.H. 03301
(603) 224-7005

Ohio Coalition for the Education of Handicapped Children
933 High St., Suite 106
Worthington, Ohio 43805
(614) 431-1307

PA Association for Children and Adults with Learning Disabilities
Box 208
Uwchland, Pa. 19408
(215) 458-8193

Parentele
5538 N. Pennsylvania St.
Indianapolis, Ind. 46220-3024
(317) 259-1654

Parent Advocacy Coalition for Educational Rights
Pacer Center, Inc.
4826 Chicago Ave.
Minneapolis, Minn. 55417-1055
(612) 827-2966

Parent Education and Assistance for Kids (PEAK)
3709 E. Platte Ave.
Suite 101
Colorado Springs, Colo. 80909
(303) 574-2345

Parent Education Network
240 Haymeadow Drive
York, Pa. 17402
(717) 845-9722
(800) 522-5827

Parent Education Network/ Florida
2215 East Henry Ave.
Tampa, Fla. 33610
(813) 239-1179

Parent Education Project
United Cerebral Palsy of Southeastern Wisconsin
230 W. Wells St. #502
Milwaukee, Wis. 53203
(414) 272-4500/1077 (TTY)
(800) 472-5525

Parent Educational Advocacy Training Center
228 South Pitt St., Suite 300
Alexandria, Va. 22314
(703) 836-2953

Parent Information Center
P.O. Box 1422
Concord, N.H. 03301
(603) 224-6299

Parent to Parent Support
ARC of King County
2230 Eighth Ave.
Seattle, Wash. 98121
(206) 622-9292

Parent Network Center
1443 Main St.
Buffalo, N.Y. 14209
(716) 882-0168

Parents Coalition for Education of New York City
24-16 Bridge Plaza S.
Lobby Floor
Long Island, N.Y. 11101
(718) 729-8866

Parents Educating Parents (PEP)
Association for Retarded Citizens of Georgia
1851 Ram Runway
College Park, Ga. 30337
(404) 761-2745

Parents Helping Parents
535 Race St. #220
San Jose, Calif. 95126
(408) 272-4774

Parents' Information Group for Exceptional Children
129 Cheerwood Drive
Baldwinsville, N.Y. 13027
(315) 423-2735

Parents Involved In Education
Developmental Center for Handicapped Persons
Utah State University
Loga , Utah 84322
(801) 750-2115

PATH
6465 Calder Ave., Suite 202
Beaumont, Texas 77707
(409) 866-4726

PIC of Delaware
Newark Medical Building
327 E. Main St., Suite 5
Newark, Del. 19711
(302) 366-0152

Pilot Parents, Inc.
1000 Sims
Council Bluffs, Iowa 51501
(712) 621-3884

Pilot Parents, Inc.
2005 N. Central, Suite 100
Phoenix, Ariz. 85004
(602) 271-4012

Project COPE
9160 Monte Vista Ave.
Montclair, Calif. 91763
(714) 621-3884
(714) 985-3116

Protection and Advocacy System
2201 San Pedro N.E.
Bldg. 4, #140
Albuquerque, N.M. 87102
(505) 888-0111

Puerto Rican Congress of New Jersey
515 S. Broad St.
Trenton, N.J. 08611
(609) 989-8888

Parents, Let's Unite for Kids
1500 N. 30th St.
Billings, Mont. 59101
(406) 657-2055

Parents of Chronically Ill Children
29 Lovell Valley Drive
Springfield, Ill. 62702
(217) 522-6810

Parents of Galactosemic Children
1 Ash Court
New City, N.Y. 10056

Parents Project
300 Enola Road
Morganton, N.C. 28655
(704) 433-2864

Parents Reaching Out Service
DC General Hospital
Department of Pediatrics
Fourth Floor, West Wing
1900 Massachusetts Ave, S.E.
Washington, D.C. 20003
(202) 727-3866

Parents Union for Public Schools
401 N. Broad St., Room 216
Philadelphia, Pa. 19108
(215) 574-0337

South Dakota Parent Connection
4200 South Louise, Suite 205
Sioux Falls, S.D. 57106
(605) 361-0952

Southeast Regional Resource Center
218 Front St.
Juneau, Alaska 99801
(907) 586-6806

Southwest Communication Resources
P.O. Box 788
Bernalillo, N.M. 87004
(505) 867-3396

Special Education Action Committee
P.O. Box 81112
Mobile, Ala. 36689-1112
(205) 478-1208
(800) 222-7322

Specialized Training of Military Parents (East)
1851 Ram Runway
College Park, Ga. 30337
(404) 767-2258

Specialized Training of Military Parents (West)
12208 Pacific Hwy. S.W.
Tacoma, Wash. 98499
(206) 588-1741

Special-Needs Parent Information Network (SPIN)
P.O. Box 2067
Augusta, Maine 04330
(207) 582-2504
(800) 325-0220

Support Group for Monosomy 9P
c/o Jonathan Storr
43304 Kipton Nickle Plate Road
LaGrange, Ohio 44050
(216) 775-4255

Task Force on Education for the Handicapped
812 E. Jefferson Blvd.
South Bend, Ind. 46617
(219) 234-7101

Team of Advocates for Special Kids (TASK)
18685 Santa Ynez
Fountain Valley, Calif. 92708
(714) 962-6332

Technical Assistance for Parent Programs (TAPP)
312 Stuart St., Second Floor
Boston, Mass. 02116
(617) 482-2915

Tri-state Organized Coalition for Persons with Disabilities
SOC Information Center
3333 Vine St., Suite 604
Cincinnati, Ohio 45220
(513) 861-2400

United Cerebral Palsy Association/ Detroit Community Service Department
17000 W. Eight Mile, Suite 380
Southfield, Mich. 48075
(313) 557-5070

United Cerebral Palsy
2701 N. Portland
Oklahoma City, Okla. 73107
(405) 947-7641

United Cerebral Palsy of Greater New Orleans
1500 Edwards Ave., Suite M
Harahan, La. 70123
(504) 733-6851

Utah Parent Information & Training Center
4984 S. 300 West St.
Murray, Utah 84107
(801) 265-9883
(800) 468-1160

Vermont Association for Retarded Citizens
37 Champlain Mill, 4th Floor
Winooski, Vt. 05404
(802) 655-4016

Washington PAVE Parent-to-Parent Training Project
6316 S. 12th St.
Tacoma, Wash. 98465
(206) 565-2266 (V/TDD)

Western New York Association for the Learning Disabled
190 Franklin St.
Buffalo, N.Y. 14202
(716) 855-1135

GOVERNMENT AGENCIES

Administration on Developmental Disabilities
Department of Health and Human Services
200 Independence Ave. S.W.
336 E. Humphrey Bldg.
Washington, D.C. 20201
(202) 245-2890

Council of State Administrators of Vocational Rehabilitation
1055 Thomas Jefferson St. N.W. Suite 401
Washington, D.C. 20006
(202) 638-4634

PROFESSIONAL ORGANIZATIONS

Academy of Dentistry for the Handicapped
211 E. Chicago Ave.
Chicago, Ill. 60611
(312) 440-2660

Accreditation Council of Services for Persons with Mental Retardation
120 Boylston St.
Suite 202
Boston, Mass. 02116
(617) 426-7909

American Academy for Cerebral Palsy & Developmental Medicine
P.O. Box 11086
Richmond, Va. 23230
(804) 355-0147

American Academy of Pediatrics
141 Northwest Point Blvd.
P.O. Box 927
Elk Grove Village, Ill. 60009-0927
(312) 228-5005

National Library Service for the Blind and Physically Handicapped
Library of Congress
1291 Taylor St. N.W.
Washington, D.C. 20542
(202) 287-9286/87

Office Of Special Education and Rehabilitation Services
Clearinghouse on the Handicapped
U.S. Dept. of Education
3132 Switzer Bldg.
Washington, D.C. 20202
(202) 732-1245
(202) 732-1250

President's Committee on Employment of the Handicapped
1111 20th St. N.W.
Room 636
Washington, D.C. 20036
(202) 653-5044
(202) 653-5050 (TDD)

National Association of Developmental Disabilities Councils
1234 Massachusetts Ave. N.W., Suite 103
Washington, D.C. 20005
(202) 347-1234

National Information Center for Handicapped Children & Youth
P.O. Box 1492
Washington, D.C. 20013
(202) 522-3332

National Institute of Child Health and Human Developmer
2A03 Bldg. 31
N.I.H.
Bethesda, Md. 20205
(301) 496-3454

National Institute of Neurological & Communicative Disorders
National Institutes of He.
Bldg. 31, Room 8A-08
Bethesda, Md. 20892
(301) 496-5751

American Association for Respiratory Care
1720 Regal Row
Dallas, Texas 75235
(214) 630-3540

American Association of University Affiliated Programs for the Developmentally Disabled
8605 Cameron St.
Suite 406
Silver Spring, Md. 20910
(301) 588-8252

American Association or Mental Deficiency
1719 Kalorama Road N.W.
Washington, D.C. 20009
(202) 387-1968

American Deafness and Rehabilitation Association
P.O. Box 55369
Little Rock, Ark. 72225
(501) 663-4617

American Medical Association
525 N. Dearborn St.
Chicago, Ill. 60610
(312) 645-5000

American Occupational Therapy Association
1383 Picard Drive
P.O. Box 1725
Rockville, Md. 20850-4375
(301) 948-9626

American Orthotic and Prosthetic Association
717 Pendleton St.
Alexandria, Va. 22314
(703) 836-7116

American Psychiatric Association
1700 18th St. N.W.
Washington, D.C. 20009
(202) 682-6000

American Physical Therapy Association
1111 N. Fairfax St.
Alexandria, Va. 22314
(703) 684-2782

American Psychological Association
1200 17th St. N.W.
Washington, D.C. 20036
(202) 955-7600

American Speech-Language Hearing Association
10801 Rockville Pike
Rockville, Md. 20852
(301) 897-5700

Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way N.E.
Seattle, Wash. 98115
(206) 523-8446

Association for the Care of Children's Health
3615 Wisconsin Ave. N.W.
Washington, D.C. 20016
(202) 244-1801

Association of Medical Rehabilitation Directors and Coordinators
87 Elm St.
Framingham, Mass. 01701
(617) 877-0517

Cleft Palate Foundation
331 Salk Hall
University of Pittsburgh
Pittsburgh, Pa. 15261
(412) 681-9620
(800) 24-CLEFT

Convention of American Instructors of the Deaf (CAID)
P.O. Box 2163
Columbia, Md. 21045
(301) 461-9988

Council for Exceptional Children
1920 Association Drive
Reston, Va. 22091
(703) 620-3660

National Association for Home Care
519 C St. N.E.
Washington, D.C. 20002
(202) 547-7424

National Association of Physical Therapists
P.O. Box 367
West Covina, Calif. 91793
(213) 332-7755

National Association of Private Residential Facilities for the Mentally Retarded
6400H Seven Corners Place
Falls Church, Va. 22044
(703) 536-3311

National Association of Private Schools for Exceptional Children
1625 Eye St. N.W., Suite 5[illegible]
Washington, D.C. 20006
(202) 223-2192

National Association of Social Workers
7981 Eastern Ave.
Silver Spring, Md. 20910
(301) 565-0333

National Association of State Directors of Special Education
2021 K St. N.W., Suite 315
Washington, D.C. 20006
(202) 296-1800

National Education Association
1201 16 St. N.W.
Washington, D.C. 20036
(202) 833-4000

National Foundation of Dentistry for the Handicapped
1250 14th St., Suite 610
Denver, Colo. 80202
(303) 573-0264

National Mental Health Association
1021 Prince St.
Alexandria, Va. 22314-2971
(703) 684-7722